

Academic respondees (anonymous)

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An additional 28 responses were received from academics who requested that their submission be used for no other purpose than in the overall analysis of responses.

UID

1414

Category of respondee

Academic researcher - Socio-economic or healthcare research

Country

United Kingdom

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

a) Improve dialogue between researchers and wider population

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

There need to be better biostatisticians throughout the whole field

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Neutral

f) Understand and investigate influence of comorbidities

Strongly Agree

g) Conduct research into effects of nutrition and frailty

Strongly Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

f) Understand and investigate influence of comorbidities on NDD

Second Priority

g) Conduct research into effects of nutrition and frailty

Third Priority

h) Determine cost-effectiveness of healthcare pathways

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Strongly Disagree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

b) Promote development of non-pharmacological interventions

Third Priority

c) Conduct multi-centre primary prevention studies

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

People have become disengaged from science and expect cures without individual participation. Everyone wants a personal gain, but we cannot always provide that and nor should we be expected to. How to change this perception is difficult to know.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

We are not there yet

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Agree

d) Develop an improved understanding of the genetic basis for NDD

Neutral

e) Determine the importance of genetic and environmental risk factors

Neutral

f) Focus research on rare hereditary forms of disease

Strongly Disagree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Improve understanding of disease stages

Second Priority

a) Understand relationship between NDD and ageing

Third Priority

c) Improve understanding of disease mechanisms

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Neutral

d) Consider regulatory approaches

Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Develop centres of excellence

Second Priority

b) Improve access to patient groups, samples and data

Third Priority

c) Improve data and sample collection

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

The context and scientific integrity of the data cannot be harmed. Open access does not mean that anything goes and that statistics from studies can be mis-used. This will harm science in the long run.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Focussing all the resources in a small number of locations can stifle research in other areas.

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Agree

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Agree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Neutral

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1421

Category of respondee

Academic researcher - Basic research

Country

United Kingdom

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Neutral

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Disagree

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Neutral

d) Research into care approaches including end of life decision-making

Neutral

e) Rethink approaches to care

Neutral

f) Understand and investigate influence of comorbidities

Neutral

g) Conduct research into effects of nutrition and frailty

Disagree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Disagree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

c) Conduct multi-centre primary prevention studies

Third Priority

e) Rethink approach to therapeutics

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Agree

e) Determine the importance of genetic and environmental risk factors

Strongly Agree

f) Focus research on rare hereditary forms of disease

Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve understanding of disease mechanisms

Second Priority

h) Develop more representative animal and cell-based models

Third Priority

d) Develop an improved understanding of the genetic basis

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Neutral

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Strongly Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Disagree

e) Develop centres of excellence

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Develop centres of excellence

Second Priority

c) Improve data and sample collection

Third Priority

a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Agree

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Strongly Agree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink patent lifetime and conduct public-private clinical trials

Second Priority

f) Review and update legislation on treatment

Third Priority

g) Review and update legislation on privacy and data disclosure

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Neutral

d) Simplify funding application systems

Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

b) Encourage open-access sharing of data and materials

Third Priority

a) Translational research needs to be promoted

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

If we want to develop treatments for these diseases, then we need to maintain a discovery pipeline, The key step is at the beginning - improving our understanding of the fundamental biology of these diseases, and the biological systems that interface with these diseases. Pharma will be able to develop treatments if we provide them with good targets from academia - bear in mind that most pharma and biotech do very little basic research

UID

1422

Category of respondee

Academic researcher - Basic research

Country

France

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

We should increase the number of researchers interested in physiology and pathophysiology to understand the basic mechanisms underlying the symptoms in neurodegenerative diseases

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Disagree

b) Survey long-term care standards and provision across Europe

Strongly Agree

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Neutral

f) Understand and investigate influence of comorbidities

Disagree

g) Conduct research into effects of nutrition and frailty

Strongly Disagree

h) Determine cost-effectiveness of healthcare pathways

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

h) Determine cost-effectiveness of healthcare pathways

Second Priority

d) Research end of life decision making

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Strongly Disagree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Strongly Agree

e) Rethink approach to therapeutics

Neutral

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Ensure better patient selection/stratification

Second Priority

a) Increase involvement of individuals in research

Third Priority

f) Support for high-risk projects

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

By a better funding of the brain banks which cannot take care of the people who want to donate their brain.
By developing better registry of patients that could be included in the clinical trials.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Disagree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Agree

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Strongly Disagree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

h) Develop more representative animal and cell-based models

Second Priority

c) Improve understanding of disease mechanisms

Third Priority

e) Determine the importance of genetic and environmental risk factors

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

b) Neuronal inflammation

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

No. The animal studies are mandatory since the cell models do not reproduce the cell/cell interactions seen in vivo in patients. I strongly disagree.

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Neutral

c) Improve data and sample collection

Strongly Disagree

d) Develop a register of persons with cognitive impairment

Strongly Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Develop centres of excellence

Second Priority

a) Improve access to, and sharing of, infrastructure and resources

Third Priority

c) Improve data and sample collection

Question 3: What can be done to facilitate increased sharing of data?

This is a difficult issue because researchers are evaluated on their publications, the patents and the grants they obtain. This is against sharing the data too early. A change in the whole system of evaluation would be needed to share the data earlier in the discovery process.

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

see above

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Yes because small groups which are excellent might not survive. Furthermore, with time the quality of such centers might decrease and it will be difficult to close a big center. Thus, a coexistence of centers of excellence and smaller research units only based on the scientific merit would be a good strategy.

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Neutral

b) Ensure greater engagement with regulators

Strongly Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Neutral

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Strongly Agree

f) Review and update legislation on treatment

Strongly Agree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Encourage industry to adopt pre-competitive approach

Second Priority

e) Rethink patent lifetime and conduct public-private clinical trials

Third Priority

g) Review and update legislation on privacy and data disclosure

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) **Translational research needs to be promoted**
Strongly Agree
- b) **Encourage open-access sharing of data and materials**
Agree
- c) **Joint academic-industry funding models**
Strongly Agree
- d) **Simplify funding application systems**
Strongly Agree
- e) **Maintain capacity for 'bottom-up' innovative funding**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

- a) Translational research needs to be promoted

Third Priority

- c) Joint academic-industry funding models

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

If sharing of material is included in the granting contract and if extra money to provide the material to the other partners is given with the grant it would improve sharing of material. A good example for that is the one of the MF Fox Foundation for Parkinson's disease. The foundation has even developed tools and animal model that are available for the community of the researchers.

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1424

Category of respondee

Academic researcher - Clinical research

Country

United Kingdom

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

In particular developing the field of the mental health consequences of neurodegenerative diseases is essential

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Strongly Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Strongly Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Research end of life decision making

Second Priority

e) Rethink approaches to care

Third Priority

h) Determine cost-effectiveness of healthcare pathways

Question 3: How would you define "care"?

Care is that support provided for health at the society and community level, the health care professional level and the governmental policy level.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Developing new approaches to care through developmental research and evaluation of these as complex interventions

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

NO the reality must be researched - i.e. advantages and disadvantages in order to allow the person and professional to choose what is best for the them, their family and wider community and/or their patient

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

- a) **Increase involvement of individuals in research**
Agree
- b) **Promote development of non-pharmacological interventions**
Strongly Agree
- c) **Conduct multi-centre primary prevention studies**
Strongly Agree
- d) **Ensure better patient selection/stratification**
Strongly Agree
- e) **Rethink approach to therapeutics**
- f) **Support for high-risk projects**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- b) Promote development of non-pharmacological interventions

Second Priority

- c) Conduct multi-centre primary prevention studies

Third Priority

- f) Support for high-risk projects

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Better education of what this research entails and how it can affect everyone and/or their families.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

WE are not yet in a position to run primary prevention trials but we are in a position to develop the methodology to create appropriate evidence based interventions that can be tested in trials

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

- a) **Understand relationship between neurodegenerative disease and ageing**
Strongly Agree
- b) **Improve understanding of disease stages**
Strongly Agree
- c) **Improve understanding of disease mechanisms**
Agree
- d) **Develop an improved understanding of the genetic basis for NDD**
Agree
- e) **Determine the importance of genetic and environmental risk factors**
Agree
- f) **Focus research on rare hereditary forms of disease**
Neutral
- g) **Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**
Strongly Agree
- h) **Develop more representative animal and cell-based models of disease**
Disagree

Question 2: Please rank the suggestions in order of priority

First Priority

- b) Improve understanding of disease stages

Second Priority

- a) Understand relationship between NDD and ageing

Third Priority

- g) Establish pan-European population-based studies

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

- d) The biological basis of behavioural and psychological symptoms

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

- a) **Redefine and standardise disease definitions and diagnosis**
Agree
- b) **Redefine and harmonise clinical endpoints and outcomes**
Strongly Agree
- c) **Develop new biomarkers**
Agree
- d) **Consider regulatory approaches**
Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

- a) [Linking to the mechanism of disease and functional endpoints](#)

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

- a) **Improve access to, and sharing of, infrastructure and resources**
Agree
- b) **Improve access to patient groups, samples and data**
Strongly Agree
- c) **Improve data and sample collection**
Agree
- d) **Develop a register of persons with cognitive impairment**
Strongly Agree
- e) **Develop centres of excellence**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- e) [Develop centres of excellence](#)

Second Priority

- d) [Develop a register of persons with cognitive impairment](#)

Third Priority

- b) [Improve access to patient groups, samples and data](#)

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

- a) **Need for evidence-based policy**
Strongly Agree
- b) **Ensure greater engagement with regulators**
Strongly Agree
- c) **Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**
Neutral
- d) **Encourage industry to adopt a pre-competitive approach to research**
Agree
- e) **Rethink patent lifetime and conduct public-private clinical trials**
Agree
- f) **Review and update legislation on treatment**
Agree
- g) **Review and update legislation on privacy and data disclosure**
Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) [Need for evidence-based policy](#)

Second Priority

- b) [Ensure greater engagement with regulators](#)

Third Priority

- c) [Facilitate research in areas outside university and hospital sectors](#)

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) **Translational research needs to be promoted**
Agree
- b) **Encourage open-access sharing of data and materials**
Agree
- c) **Joint academic-industry funding models**
Agree
- d) **Simplify funding application systems**
Agree
- e) **Maintain capacity for 'bottom-up' innovative funding**
Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Translational research needs to be promoted

Second Priority

- c) Joint academic-industry funding models

Third Priority

- e) Maintain capacity for 'bottom-up' innovative funding

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1433

Category of respondee

Academic researcher - Clinical research

Country

United Kingdom

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

d) Increase training for translational and clinician-scientists

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Strongly Agree

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Strongly Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

b) Survey long-term care standards and provision across Europe

Second Priority

e) Rethink approaches to care

Third Priority

c) Research into the needs of carers

Question 3: How would you define "care"?

Maximising quality of life

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Neutral

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

f) Support for high-risk projects

Third Priority

e) Rethink approach to therapeutics

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Explain the value

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Strongly Agree

e) Determine the importance of genetic and environmental risk factors

Strongly Agree

f) Focus research on rare hereditary forms of disease

Neutral

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve understanding of disease mechanisms

Second Priority

h) Develop more representative animal and cell-based models

Third Priority

d) Develop an improved understanding of the genetic basis

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

a) Interactions between cells and their surrounding intra- and extracellular environment

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Yes, where there is no credible animal model

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Neutral

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

d) Consider regulatory approaches

Strongly Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

b) Linking to treatment responses

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve data and sample collection

Second Priority

b) Improve access to patient groups, samples and data

Third Priority

e) Develop centres of excellence

Question 3: What can be done to facilitate increased sharing of data?

Fast-track international customs procedure to prevent thawing of valuable biofluid samples

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Factor in collaboration and data-sharing as a positive point in the institutional research assessment exercise.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Exclusivity

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Strongly Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Agree

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Agree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Ensure greater engagement with regulators

Second Priority

g) Review and update legislation on privacy and data disclosure

Third Priority

f) Review and update legislation on treatment

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

d) Simplify funding application systems

Third Priority

c) Joint academic-industry funding models

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1434

Category of respondent

Academic researcher - Basic research

Country

United Kingdom

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Neutral

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

d) Increase training for translational and clinician-scientists

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Strongly Agree

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Disagree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Disagree

g) Conduct research into effects of nutrition and frailty

Strongly Disagree

h) Determine cost-effectiveness of healthcare pathways

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approaches to care

Second Priority

b) Survey long-term care standards and provision across Europe

Third Priority

h) Determine cost-effectiveness of healthcare pathways

Question 3: How would you define "care"?

Medical, social and psychosocial interventions designed to treat, support or otherwise look after an individual (or individuals) with a particular disease or disorder.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Facilitate research and innovation in this area - make it attractive

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

- b) Promote development of non-pharmacological interventions**
Strongly Agree
- c) Conduct multi-centre primary prevention studies**
Strongly Agree
- d) Ensure better patient selection/stratification**
Strongly Agree
- e) Rethink approach to therapeutics**
Strongly Agree
- f) Support for high-risk projects**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- b) Promote development of non-pharmacological interventions

Second Priority

- a) Increase involvement of individuals in research

Third Priority

- f) Support for high-risk projects

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

- Training of front-line clinicians. Establishment of large-scale brain banks with appropriate expertise.
- Incentivise health care systems financially by enrolment in clinical trials.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

- a) Understand relationship between neurodegenerative disease and ageing**
Strongly Agree
- b) Improve understanding of disease stages**
Agree
- c) Improve understanding of disease mechanisms**
Strongly Agree
- d) Develop an improved understanding of the genetic basis for NDD**
Neutral
- e) Determine the importance of genetic and environmental risk factors**
Agree
- f) Focus research on rare hereditary forms of disease**
Strongly Disagree
- g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**
Neutral
- h) Develop more representative animal and cell-based models of disease**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Understand relationship between NDD and ageing

Second Priority

- c) Improve understanding of disease mechanisms

Third Priority

- h) Develop more representative animal and cell-based models

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

- d) The biological basis of behavioural and psychological symptoms

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

- a) Redefine and standardise disease definitions and diagnosis**
Neutral
- b) Redefine and harmonise clinical endpoints and outcomes**
Neutral
- c) Develop new biomarkers**

Strongly Agree

d) Consider regulatory approaches

Disagree

Question 2: Which of the following do you think is most important in terms of biomarkers?

c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Strongly Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Develop centres of excellence

Second Priority

c) Improve data and sample collection

Third Priority

a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?

Large-scale infrastructure support

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Needs some way to ensure that people who contribute to the data collection are appropriately recognised. Risk is that open access will de-incentivise people who actually collect the data - they could instead just wait until the data become available when someone else collects it.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Significant political risks associated with any EU-wide initiative (every country will want one, just like airlines, even if it is ridiculous).

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Neutral

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Neutral

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Ensure greater engagement with regulators

Second Priority

d) Encourage industry to adopt pre-competitive approach

Third Priority

e) Rethink patent lifetime and conduct public-private clinical trials

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) **Translational research needs to be promoted**
Agree
- b) **Encourage open-access sharing of data and materials**
Disagree
- c) **Joint academic-industry funding models**
Agree
- d) **Simplify funding application systems**
Strongly Agree
- e) **Maintain capacity for 'bottom-up' innovative funding**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

- d) Simplify funding application systems

Third Priority

- c) Joint academic-industry funding models

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1436

Category of respondee

Academic researcher - Basic research

Country

Turkey

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

c) Increase overall numbers of researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Strongly Agree

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Strongly Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Strongly Agree

g) Conduct research into effects of nutrition and frailty

Strongly Agree

h) Determine cost-effectiveness of healthcare pathways

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Research end of life decision making

Second Priority

a) Define the term 'care'

Third Priority

b) Survey long-term care standards and provision across Europe

Question 3: How would you define "care"?

High quality of; - Life standards of the patient - Therapeutics - Who take care of the Alzheimer's patient

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Education is needed for any of researchers who works on AD and who take care of the patient

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Neutral

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Strongly Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

e) Rethink approach to therapeutics

Third Priority

f) Support for high-risk projects

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

By organizing public conference, by advertisements

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Each center should organize their own group and select a speaker for themselves to present them

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Strongly Agree

e) Determine the importance of genetic and environmental risk factors

Strongly Agree

f) Focus research on rare hereditary forms of disease

Strongly Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Strongly Agree

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Understand relationship between NDD and ageing

Second Priority

h) Develop more representative animal and cell-based models

Third Priority

e) Determine the importance of genetic and environmental risk factors

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Conditions and models should be very similar to in vivo structures Cells should be selected as human originated Models should be consist of the same cellular mechanisms, GF, cytokines or/and drug transporters with brain and brain related tissues

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Strongly Agree

b) Redefine and harmonise clinical endpoints and outcomes

Strongly Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Strongly Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Develop centres of excellence

Second Priority

a) Improve access to, and sharing of, infrastructure and resources

Third Priority

d) Develop a register of persons with cognitive impairment

Question 3: What can be done to facilitate increased sharing of data?

Design of a web page which can include all data are needed by researchers, and healthcare professionals. Subscription should be necessary.

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Open access is not needed.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

No

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Agree

d) Encourage industry to adopt a pre-competitive approach to research

Strongly Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Strongly Agree

f) Review and update legislation on treatment

Strongly Agree

g) Review and update legislation on privacy and data disclosure

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Encourage industry to adopt pre-competitive approach

Second Priority

g) Review and update legislation on privacy and data disclosure

Third Priority

f) Review and update legislation on treatment

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) **Translational research needs to be promoted**
Strongly Agree
- b) **Encourage open-access sharing of data and materials**
Neutral
- c) **Joint academic-industry funding models**
Strongly Agree
- d) **Simplify funding application systems**
Agree
- e) **Maintain capacity for 'bottom-up' innovative funding**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- c) Joint academic-industry funding models

Second Priority

- e) Maintain capacity for 'bottom-up' innovative funding

Third Priority

- a) Translational research needs to be promoted

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Those kind of data can be obtained by several different projects. So that who can perform some research/study as a part of the project, they can reach to the knowledge they can need.

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Projects should be proposed on Diagnostics, basic research, education of health care professionals, education of people.

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1439

Category of respondee

Academic researcher - Basic research

Country

United Kingdom

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

b) Survey long-term care standards and provision across Europe

c) Research into the needs of carers

d) Research into care approaches including end of life decision-making

e) Rethink approaches to care

f) Understand and investigate influence of comorbidities

g) Conduct research into effects of nutrition and frailty

h) Determine cost-effectiveness of healthcare pathways

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Neutral

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

- a) **Understand relationship between neurodegenerative disease and ageing**
Strongly Agree
- b) **Improve understanding of disease stages**
Agree
- c) **Improve understanding of disease mechanisms**
Strongly Agree
- d) **Develop an improved understanding of the genetic basis for NDD**
Agree
- e) **Determine the importance of genetic and environmental risk factors**
Neutral
- f) **Focus research on rare hereditary forms of disease**
Disagree
- g) **Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**
Neutral
- h) **Develop more representative animal and cell-based models of disease**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- h) Develop more representative animal and cell-based models

Second Priority

- c) Improve understanding of disease mechanisms

Third Priority

- a) Understand relationship between NDD and ageing

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

- b) Neuronal inflammation

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

I do not think it would ever (OK, hardly ever) be acceptable to omit animal models. The possibility for unexpected effects is too great. Also, it is necessary to show efficacy in animal models before the cost and risk of clinical trials is contemplated.

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

- a) **Redefine and standardise disease definitions and diagnosis**
Agree
- b) **Redefine and harmonise clinical endpoints and outcomes**
Agree
- c) **Develop new biomarkers**
Agree
- d) **Consider regulatory approaches**
Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

- a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

- a) **Improve access to, and sharing of, infrastructure and resources**
Strongly Agree
- b) **Improve access to patient groups, samples and data**
Agree
- c) **Improve data and sample collection**

Neutral

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Improve access to, and sharing of, infrastructure and resources

Second Priority

e) Develop centres of excellence

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

b) Ensure greater engagement with regulators

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

d) Encourage industry to adopt a pre-competitive approach to research

e) Rethink patent lifetime and conduct public-private clinical trials

f) Review and update legislation on treatment

g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Translational research needs to be promoted

Second Priority

e) Maintain capacity for 'bottom-up' innovative funding

Third Priority

c) Joint academic-industry funding models

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

The role of inflammation in neurodegeneration is increasingly recognised, but it is still very under-recognised, given its increasingly obvious importance.

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1477

Category of respondee

Academic researcher - Basic research

Country

Norway

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Neutral

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

d) Increase training for translational and clinician-scientists

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Neutral

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

f) Understand and investigate influence of comorbidities on NDD

Second Priority

h) Determine cost-effectiveness of healthcare pathways

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

c) Conduct multi-centre primary prevention studies

Second Priority

d) Ensure better patient selection/stratification

Third Priority

a) Increase involvement of individuals in research

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Strongly Agree

e) Determine the importance of genetic and environmental risk factors

Strongly Agree

f) Focus research on rare hereditary forms of disease

Strongly Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve understanding of disease mechanisms

Second Priority

f) Focus research on rare hereditary forms of disease

Third Priority

e) Determine the importance of genetic and environmental risk factors

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

- a) **Improve access to, and sharing of, infrastructure and resources**
Strongly Agree
- b) **Improve access to patient groups, samples and data**
Strongly Agree
- c) **Improve data and sample collection**
Strongly Agree
- d) **Develop a register of persons with cognitive impairment**
Agree
- e) **Develop centres of excellence**
Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

- b) Improve access to patient groups, samples and data

Second Priority

- c) Improve data and sample collection

Third Priority

- a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

- a) **Need for evidence-based policy**
Agree
- b) **Ensure greater engagement with regulators**
Neutral
- c) **Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**
Agree
- d) **Encourage industry to adopt a pre-competitive approach to research**
Neutral
- e) **Rethink patent lifetime and conduct public-private clinical trials**
Agree
- f) **Review and update legislation on treatment**
Agree
- g) **Review and update legislation on privacy and data disclosure**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- g) Review and update legislation on privacy and data disclosure

Second Priority

- a) Need for evidence-based policy

Third Priority

- c) Facilitate research in areas outside university and hospital sectors

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) **Translational research needs to be promoted**
Strongly Agree
- b) **Encourage open-access sharing of data and materials**
Strongly Agree
- c) **Joint academic-industry funding models**
Agree
- d) **Simplify funding application systems**
Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Translational research needs to be promoted

Second Priority

e) Maintain capacity for 'bottom-up' innovative funding

Third Priority

d) Simplify funding application systems

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1503

Category of respondee

Academic researcher - Basic research

Country

Switzerland

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Neutral

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

d) Increase training for translational and clinician-scientists

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Neutral

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approaches to care

Second Priority

c) Research into the needs of carers

Third Priority

b) Survey long-term care standards and provision across Europe

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Strongly Agree

c) Conduct multi-centre primary prevention studies

Strongly Agree

d) Ensure better patient selection/stratification

Strongly Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

f) Support for high-risk projects

Second Priority

b) Promote development of non-pharmacological interventions

Third Priority

d) Ensure better patient selection/stratification

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Neutral

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Disagree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Strongly Agree

h) Develop more representative animal and cell-based models of disease

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

g) Establish pan-European population-based studies

Second Priority

e) Determine the importance of genetic and environmental risk factors

Third Priority

h) Develop more representative animal and cell-based models

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

d) The biological basis of behavioural and psychological symptoms

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

In terminal disease in a form of compassionate use of highly experimental treatments that have not been tested in animals may be acceptable. Full decision-making capacity or advanced directives would absolutely be required to go down such a road.

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Disagree

Question 2: Which of the following do you think is most important in terms of biomarkers?

b) Linking to treatment responses

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Strongly Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve data and sample collection

Second Priority

b) Improve access to patient groups, samples and data

Third Priority

e) Develop centres of excellence

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Neutral

b) Ensure greater engagement with regulators

Neutral

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Strongly Agree

d) Encourage industry to adopt a pre-competitive approach to research

Strongly Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Strongly Agree

f) Review and update legislation on treatment

Strongly Agree

g) Review and update legislation on privacy and data disclosure

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Facilitate research in areas outside university and hospital sectors

Second Priority

f) Review and update legislation on treatment

Third Priority

g) Review and update legislation on privacy and data disclosure

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Strongly Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

d) Simplify funding application systems

Third Priority

a) Translational research needs to be promoted

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1543

Category of respondee

Academic researcher - Basic research

Country

United Kingdom

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Neutral

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

d) Increase training for translational and clinician-scientists

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Developing suitable animal models to test potential therapies

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Strongly Agree

d) Research into care approaches including end of life decision-making

Strongly Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Strongly Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

g) Conduct research into effects of nutrition and frailty

Second Priority

d) Research end of life decision making

Third Priority

c) Research into the needs of carers

Question 3: How would you define "care"?

Looking after the physical health and psychological wellbeing of the patients

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Care system overhaul should also look at patient access to medication whilst in hospital. Drug scheduling for say a Parkinson's patients may not comply with standard medication ward rounds. Patients should be able to self medicate with clinical supervision.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Take a close examination of what are the major advantages of patients being treated at home e.g. patient familiar surrounding, family etc and disadvantages. Put resources into enabling patients to be cared at home for the positive benefits. However, for certain forms of treatment it is not always possible to treat at home, hence there should be clear demarcation of what can be done at home and what cannot and put in place the resources to promote appropriate care whether at home or in a hospital.

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

- a) **Increase involvement of individuals in research**
Strongly Agree
- b) **Promote development of non-pharmacological interventions**
Agree
- c) **Conduct multi-centre primary prevention studies**
Strongly Agree
- d) **Ensure better patient selection/stratification**
Strongly Agree
- e) **Rethink approach to therapeutics**
Strongly Agree
- f) **Support for high-risk projects**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- f) Support for high-risk projects

Second Priority

- c) Conduct multi-centre primary prevention studies

Third Priority

- d) Ensure better patient selection/stratification

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Better advertising of research/donor programmes. More engagement between basic scientists and patients to de-mistify the science, thus encouraging them to take part. Great publicity of the advances research is making and what excellent research is being carried out on donated tissue. Publicise it not only disease tissue researchers require, they also require tissue from healthy individuals to compare to.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

- Influence of diet and lifestyle.

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

- a) **Understand relationship between neurodegenerative disease and ageing**
Strongly Agree
- b) **Improve understanding of disease stages**
Agree
- c) **Improve understanding of disease mechanisms**
Strongly Agree
- d) **Develop an improved understanding of the genetic basis for NDD**
Agree
- e) **Determine the importance of genetic and environmental risk factors**
Strongly Agree
- f) **Focus research on rare hereditary forms of disease**
Neutral
- g) **Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**
Strongly Agree
- h) **Develop more representative animal and cell-based models of disease**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- h) Develop more representative animal and cell-based models

Second Priority

- a) Understand relationship between NDD and ageing

Third Priority

- c) Improve understanding of disease mechanisms

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

- a) Interactions between cells and their surrounding intra- and extracellular environment

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

I cannot see any circumstance where a treatment can progress from cell lines straight to human trials since there are many factors which need to be tested in intact physiological systems e.g. toxicology, pharmacokinetics etc etc

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Neutral

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Neutral

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Develop centres of excellence

Second Priority

b) Improve access to patient groups, samples and data

Third Priority

c) Improve data and sample collection

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Large centres are not sometimes the best facilities for major discoveries. You need centres of excellence but still reasonable funding for highly successful individuals

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Agree

d) Encourage industry to adopt a pre-competitive approach to research

Strongly Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Agree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Encourage industry to adopt pre-competitive approach

Second Priority

g) Review and update legislation on privacy and data disclosure

Third Priority

b) Ensure greater engagement with regulators

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

d) Simplify funding application systems

Third Priority

a) Translational research needs to be promoted

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1544

Category of respondee

Academic researcher - Basic research

Country

Belgium

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Neutral

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Disagree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Neutral

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Disagree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

h) Determine cost-effectiveness of healthcare pathways

Second Priority

d) Research end of life decision making

Third Priority

f) Understand and investigate influence of comorbidities on NDD

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Disagree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Strongly Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Ensure better patient selection/stratification

Second Priority

a) Increase involvement of individuals in research

Third Priority

c) Conduct multi-centre primary prevention studies

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Neutral

e) Determine the importance of genetic and environmental risk factors

Neutral

f) Focus research on rare hereditary forms of disease

Strongly Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Understand relationship between NDD and ageing

Second Priority

c) Improve understanding of disease mechanisms

Third Priority

h) Develop more representative animal and cell-based models

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

a) Interactions between cells and their surrounding intra- and extracellular environment

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

- a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Neutral

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

e) Develop centres of excellence

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Improve access to patient groups, samples and data

Second Priority

c) Improve data and sample collection

Third Priority

a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Neutral

d) Encourage industry to adopt a pre-competitive approach to research

Strongly Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Strongly Agree

f) Review and update legislation on treatment

Strongly Agree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Encourage industry to adopt pre-competitive approach

Second Priority

a) Need for evidence-based policy

Third Priority

f) Review and update legislation on treatment

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Strongly Agree

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1552

Category of respondee

Academic researcher - Clinical research

Country

United Kingdom

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Neutral

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

c) Increase overall numbers of researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Disagree

b) Survey long-term care standards and provision across Europe

Neutral

c) Research into the needs of carers

Neutral

d) Research into care approaches including end of life decision-making

Neutral

e) Rethink approaches to care

Neutral

f) Understand and investigate influence of comorbidities

Neutral

g) Conduct research into effects of nutrition and frailty

Disagree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

f) Understand and investigate influence of comorbidities on NDD

Second Priority

h) Determine cost-effectiveness of healthcare pathways

Third Priority

g) Conduct research into effects of nutrition and frailty

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Neutral

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Disagree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

f) Support for high-risk projects

Third Priority

d) Ensure better patient selection/stratification

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Neutral

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Strongly Disagree

e) Determine the importance of genetic and environmental risk factors

Disagree

f) Focus research on rare hereditary forms of disease

Disagree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Strongly Agree

h) Develop more representative animal and cell-based models of disease

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve understanding of disease mechanisms

Second Priority

g) Establish pan-European population-based studies

Third Priority

b) Improve understanding of disease stages

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

a) Interactions between cells and their surrounding intra- and extracellular environment

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Neutral

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Disagree

Question 2: Which of the following do you think is most important in terms of biomarkers?

- c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Disagree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Neutral

e) Develop centres of excellence

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

b) Improve access to patient groups, samples and data

Second Priority

c) Improve data and sample collection

Third Priority

a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Strongly Disagree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Neutral

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Strongly Agree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Need for evidence-based policy

Second Priority

d) Encourage industry to adopt pre-competitive approach

Third Priority

f) Review and update legislation on treatment

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Neutral

b) Encourage open-access sharing of data and materials

Disagree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Agree

e) Maintain capacity for 'bottom-up' innovative funding
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

c) Joint academic-industry funding models

Third Priority

d) Simplify funding application systems

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Strategic funding will never bear fruit. Funding should be available to those with good ideas and track records irrespective of perceived short and medium term priorities. Fund innovation and excellence.

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Good quality peer review - ideally no longer anonymous.

Question 3: Is there anything else you would like to tell us?

UID

1555

Category of respondee

Academic researcher - Clinical research

Country

Norway

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

b) Improve education and training of healthcare professionals

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Strongly Agree

d) Research into care approaches including end of life decision-making

Strongly Agree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Neutral

h) Determine cost-effectiveness of healthcare pathways

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approaches to care

Second Priority

c) Research into the needs of carers

Third Priority

a) Define the term 'care'

Question 3: How would you define "care"?

I really do not know, and therefore I have responded to one of the question that we should together find an appropriate definition. But for sure I believe that a person centred approach is of utmost importance

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

A person centred approach must be given priority and co-operation between professional and family caregivers must be stronger, and of course to give good quality care the leadership of nursing homes, day care centres etc must be optimal.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

To provide good care at home a person centred approach must be taken, giving the patient and the family carers more power. Each individual has their own priorities and these must be fulfilled as much as possible

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

- a) **Increase involvement of individuals in research**
Strongly Agree
- b) **Promote development of non-pharmacological interventions**
Strongly Agree
- c) **Conduct multi-centre primary prevention studies**
Strongly Agree
- d) **Ensure better patient selection/stratification**
Strongly Agree
- e) **Rethink approach to therapeutics**
Strongly Agree
- f) **Support for high-risk projects**
Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

- b) Promote development of non-pharmacological interventions

Second Priority

- e) Rethink approach to therapeutics

Third Priority

- c) Conduct multi-centre primary prevention studies

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

We should raise the general awareness of the various diseases, just like what have been done for Cancer the last 50 years

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Life style factors and treatment of disorders/risk factors that could lead the cerebrovascular changes - and explore the importance of food intake (antioxydants etc..)

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

- a) **Understand relationship between neurodegenerative disease and ageing**
Strongly Agree
- b) **Improve understanding of disease stages**
Neutral
- c) **Improve understanding of disease mechanisms**
Agree
- d) **Develop an improved understanding of the genetic basis for NDD**
Neutral
- e) **Determine the importance of genetic and environmental risk factors**
Strongly Agree
- f) **Focus research on rare hereditary forms of disease**
Neutral
- g) **Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**
Agree
- h) **Develop more representative animal and cell-based models of disease**
Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Understand relationship between NDD and ageing

Second Priority

- c) Improve understanding of disease mechanisms

Third Priority

- e) Determine the importance of genetic and environmental risk factors

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

- c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

?? This is difficult to answer for a clinician

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Strongly Agree

b) Redefine and harmonise clinical endpoints and outcomes

Strongly Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

b) Linking to treatment responses

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Strongly Agree

e) Develop centres of excellence

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

d) Develop a register of persons with cognitive impairment

Second Priority

a) Improve access to, and sharing of, infrastructure and resources

Third Priority

b) Improve access to patient groups, samples and data

Question 3: What can be done to facilitate increased sharing of data?

To establish a European Registry

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

I am not sure that this is a good idea. It would be better to have a common Registry with a steering group that in a way could give any research group access to data according to a good quality research protocol

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Yes. There are 'Kings' among us

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Neutral

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Agree

d) Encourage industry to adopt a pre-competitive approach to research

Neutral

e) Rethink patent lifetime and conduct public-private clinical trials

Neutral

f) Review and update legislation on treatment

Neutral

g) Review and update legislation on privacy and data disclosure

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Need for evidence-based policy

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) Translational research needs to be promoted**
Strongly Agree
- b) Encourage open-access sharing of data and materials**
Neutral
- c) Joint academic-industry funding models**
Agree
- d) Simplify funding application systems**
Strongly Agree
- e) Maintain capacity for 'bottom-up' innovative funding**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Translational research needs to be promoted

Second Priority

- c) Joint academic-industry funding models

Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

We need long-term, very long-term projects as the neurodegenerative disorders all have long duration. We need more knowledge about the preclinical phase of NDD, such as the dementia disorders

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Give fundings for very long term follow-up (observational studies) and preventive studies

Question 3: Is there anything else you would like to tell us?

Yes. the quality of care for person with dementia must improve and a person centered care approach must be introduced

UID

1566

Category of respondee

Academic researcher - Basic research

Country

Belgium

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Disagree

b) Improve education and training of healthcare professionals

Neutral

c) Increase numbers of neurodegenerative disease (NDD) researchers

Neutral

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

d) Increase training for translational and clinician-scientists

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Neutral

c) Research into the needs of carers

Neutral

d) Research into care approaches including end of life decision-making

Neutral

e) Rethink approaches to care

f) Understand and investigate influence of comorbidities

Neutral

g) Conduct research into effects of nutrition and frailty

Neutral

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Agree

d) Develop an improved understanding of the genetic basis for NDD

Neutral

e) Determine the importance of genetic and environmental risk factors

Neutral

f) Focus research on rare hereditary forms of disease

Strongly Disagree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Neutral

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

h) Develop more representative animal and cell-based models

Second Priority

c) Improve understanding of disease mechanisms

Third Priority

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

d) The biological basis of behavioural and psychological symptoms

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Strongly Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Agree

- b) Improve access to patient groups, samples and data**
Strongly Agree
- c) Improve data and sample collection**
Strongly Agree
- d) Develop a register of persons with cognitive impairment**
Strongly Agree
- e) Develop centres of excellence**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Develop centres of excellence

Second Priority

b) Improve access to patient groups, samples and data

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Disagree

d) Encourage industry to adopt a pre-competitive approach to research

Neutral

e) Rethink patent lifetime and conduct public-private clinical trials

Neutral

f) Review and update legislation on treatment

Neutral

g) Review and update legislation on privacy and data disclosure

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Strongly Agree

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

Agree

e) Maintain capacity for 'bottom-up' innovative funding

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1579

Category of respondee

Academic researcher - Basic research

Country

United Kingdom

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Disagree

b) Survey long-term care standards and provision across Europe

Neutral

c) Research into the needs of carers

Neutral

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Strongly Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approaches to care

Second Priority

d) Research end of life decision making

Third Priority

h) Determine cost-effectiveness of healthcare pathways

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Neutral

b) Promote development of non-pharmacological interventions

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Neutral

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

f) Support for high-risk projects

Second Priority

d) Ensure better patient selection/stratification

Third Priority

b) Promote development of non-pharmacological interventions

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Agree

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Disagree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Neutral

h) Develop more representative animal and cell-based models of disease

Disagree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve understanding of disease mechanisms

Second Priority

b) Improve understanding of disease stages

Third Priority

a) Understand relationship between NDD and ageing

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

d) The biological basis of behavioural and psychological symptoms

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Strongly Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Neutral

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

- a) **Improve access to, and sharing of, infrastructure and resources**
Agree
- b) **Improve access to patient groups, samples and data**
Agree
- c) **Improve data and sample collection**
Agree
- d) **Develop a register of persons with cognitive impairment**
Neutral
- e) **Develop centres of excellence**
Disagree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Improve access to, and sharing of, infrastructure and resources

Second Priority

- b) Improve access to patient groups, samples and data

Third Priority

- c) Improve data and sample collection

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

- a) **Need for evidence-based policy**
Agree
- b) **Ensure greater engagement with regulators**
Neutral
- c) **Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**
Neutral
- d) **Encourage industry to adopt a pre-competitive approach to research**
Strongly Agree
- e) **Rethink patent lifetime and conduct public-private clinical trials**
Agree
- f) **Review and update legislation on treatment**
Agree
- g) **Review and update legislation on privacy and data disclosure**
Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Need for evidence-based policy

Second Priority

- d) Encourage industry to adopt pre-competitive approach

Third Priority

- f) Review and update legislation on treatment

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) **Translational research needs to be promoted**
Neutral
- b) **Encourage open-access sharing of data and materials**
Strongly Agree
- c) **Joint academic-industry funding models**
Agree
- d) **Simplify funding application systems**
Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

d) Simplify funding application systems

Third Priority

a) Translational research needs to be promoted

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1587

Category of respondee

Academic researcher - Clinical research

Country

Ireland

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

d) Increase training for translational and clinician-scientists

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Delirium- understanding amongst healthcare professionals, identification and management; Stigma of mental illness and cognitive decline; Burden of delirium and dementia on health services and resources

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approaches to care

Second Priority

h) Determine cost-effectiveness of healthcare pathways

Third Priority

d) Research end of life decision making

Question 3: How would you define "care"?

'Care' could be defined as the service and support a patient and their family needs, has access to and/ or utilises. It encompasses services across a number of domains including medical, nursing and other allied health disciplines, personal and comfort needs and transport and can be domiciliary, within hospitals, hospices and long-stay or step-down institutions.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Neutral

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Neutral

d) Ensure better patient selection/stratification

Disagree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approach to therapeutics

Second Priority

b) Promote development of non-pharmacological interventions

Third Priority

f) Support for high-risk projects

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Education about how research has helped us to date, using concrete examples, and also explaining what the potential for the future may hold in terms of medical advancements and improvements to care. This education should be targeted at all ages and backgrounds, for example TV programmes and advertisements

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Agree

d) Develop an improved understanding of the genetic basis for NDD

Neutral

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Neutral

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Understand relationship between NDD and ageing

Second Priority

b) Improve understanding of disease stages

Third Priority

e) Determine the importance of genetic and environmental risk factors

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Neutral

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

b) Linking to treatment responses

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve data and sample collection

Second Priority

a) Improve access to, and sharing of, infrastructure and resources

Third Priority

b) Improve access to patient groups, samples and data

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Agree

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Neutral

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Need for evidence-based policy

Second Priority

b) Ensure greater engagement with regulators

Third Priority

c) Facilitate research in areas outside university and hospital sectors

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Neutral

e) Maintain capacity for 'bottom-up' innovative funding

Question 2: Please rank the suggestions in order of priority

First Priority

a) Translational research needs to be promoted

Second Priority

b) Encourage open-access sharing of data and materials

Third Priority

c) Joint academic-industry funding models

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1594

Category of respondent

Academic researcher - Socio-economic or healthcare research

Country

United Kingdom

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Neutral

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

c) Increase overall numbers of researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Neutral

c) Research into the needs of carers

Neutral

d) Research into care approaches including end of life decision-making

Neutral

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Neutral

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approaches to care

Second Priority

f) Understand and investigate influence of comorbidities on NDD

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Strongly Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

c) Conduct multi-centre primary prevention studies

Second Priority

Third Priority

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Interventions that can be delivered in a primary care setting, that build on existing approaches of prevention (e.g. for CVD)

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Neutral

c) Improve understanding of disease mechanisms

Agree

d) Develop an improved understanding of the genetic basis for NDD

Agree

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Neutral

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve understanding of disease mechanisms

Second Priority

Third Priority

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Neutral

e) Develop centres of excellence

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Agree

d) Encourage industry to adopt a pre-competitive approach to research

e) Rethink patent lifetime and conduct public-private clinical trials

Neutral

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Agree

e) Maintain capacity for 'bottom-up' innovative funding

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1622

Category of respondee

Academic researcher - Basic research

Country

Ireland

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Question 2: If you had to choose one priority from the points above what would it be?

d) Increase training for translational and clinician-scientists

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Strongly Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Strongly Agree

g) Conduct research into effects of nutrition and frailty

Strongly Agree

h) Determine cost-effectiveness of healthcare pathways

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

f) Understand and investigate influence of comorbidities on NDD

Second Priority

h) Determine cost-effectiveness of healthcare pathways

Third Priority

g) Conduct research into effects of nutrition and frailty

Question 3: How would you define "care"?

I am a basic researcher and do not care for patients or indeed family members. My view is that care should encompass medical, social/intellectual, physical and dietary needs of the patient

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

As a basic researcher interested in acute exacerbations of chronic disease, I believe careful monitoring of mental status is a key element of care since. Episodes of delirium, whether hyperactive or hypoactive (and therefore not obvious), are strong prognostic indicators of cognitive decline. Therefore 'care' should certainly include careful monitoring for mental status changes.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

- a) **Increase involvement of individuals in research**
Agree
- b) **Promote development of non-pharmacological interventions**
Agree
- c) **Conduct multi-centre primary prevention studies**
Agree
- d) **Ensure better patient selection/stratification**
Strongly Agree
- e) **Rethink approach to therapeutics**
Strongly Agree
- f) **Support for high-risk projects**
Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

- e) Rethink approach to therapeutics

Second Priority

- d) Ensure better patient selection/stratification

Third Priority

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

The trials of NSAID effects in Alzheimer's disease patients have been tested in patients, largely lacking any co-morbidities. Since systemic inflammatory disease can contribute to progression of brain disease I would like to see such trials done on a truly representative group of AD patients, in a multicentre study

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

- a) **Understand relationship between neurodegenerative disease and ageing**
Strongly Agree
- b) **Improve understanding of disease stages**
Agree
- c) **Improve understanding of disease mechanisms**
Strongly Agree
- d) **Develop an improved understanding of the genetic basis for NDD**
Agree
- e) **Determine the importance of genetic and environmental risk factors**
Strongly Agree
- f) **Focus research on rare hereditary forms of disease**
Neutral
- g) **Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**
- h) **Develop more representative animal and cell-based models of disease**

Question 2: Please rank the suggestions in order of priority

First Priority

- e) Determine the importance of genetic and environmental risk factors

Second Priority

- c) Improve understanding of disease mechanisms

Third Priority

- a) Understand relationship between NDD and ageing

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

- d) The biological basis of behavioural and psychological symptoms

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Though animal models are not always predictive, there are few examples of cell-based models predicting appropriate therapeutic strategies for humans. What is required is an honest appraisal of why animal models have performed poorly and what aspects they may lack in order to offer a reliable testing ground for new therapeutics.

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

- a) **Redefine and standardise disease definitions and diagnosis**

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Strongly Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

b) Improve access to patient groups, samples and data

Second Priority

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Open access data would be very helpful in some situations. Repetition/replication of work remains the gold standard, rather than the temptation to pore over others data in the hope of reinterpreting or refuting it. However, a standard mechanism that facilitates access to original data would be very useful.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Centres of excellence can, in theory, provide an excellent focus of expertise. However, they can erroneously provide a 'seal of approval' for the activities of one centre and risk marginalising the research and views of those who are not included. It may create an environment in which new ideas from 'outside the box' are too easily disregarded. In effect, they may concentrate funding on a group of 'members'.

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

b) Ensure greater engagement with regulators

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

d) Encourage industry to adopt a pre-competitive approach to research

e) Rethink patent lifetime and conduct public-private clinical trials

f) Review and update legislation on treatment

g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Translational research needs to be promoted

Second Priority

e) Maintain capacity for 'bottom-up' innovative funding

Third Priority

b) Encourage open-access sharing of data and materials

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Since it is widely accepted that delirium is a frequent complication of dementia AND that such episodes accelerate the decline of cognitive function in these individuals it is imperative that efforts to understand this condition are stepped up. Likewise, given that co-morbidity is a fact of aging, much greater emphasis must be put on its contribution to neurodegenerative disease in both basic and clinical research.

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Some of this could be implemented through funding mechanisms for this research (ie more funding for delirium research (basic and clinical) and more funding for research into impact of co-morbidity on chronic brain disease. The need for clinical trials to address this aspect of disease could be examined through the ethical review and regulatory processes.

Question 3: Is there anything else you would like to tell us?

UID

1623

Category of respondee

Academic researcher - Basic research

Country

Belgium

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Neutral

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Neutral

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Neutral

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approach to therapeutics

Second Priority

Third Priority

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Agree

e) Determine the importance of genetic and environmental risk factors

Strongly Agree

f) Focus research on rare hereditary forms of disease

Disagree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

h) Develop more representative animal and cell-based models

Second Priority

b) Improve understanding of disease stages

Third Priority

d) Develop an improved understanding of the genetic basis

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

b) Neuronal inflammation

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

No

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

b) Linking to treatment responses

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Strongly Agree

e) Develop centres of excellence

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Improve access to, and sharing of, infrastructure and resources

Second Priority

d) Develop a register of persons with cognitive impairment

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Smaller and less funded groups will fall out of the system !

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Neutral

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Agree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Simplify funding application systems

Second Priority
Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1638

Category of respondee

Academic researcher - Basic research

Country

Belgium

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

a) Improve dialogue between researchers and wider population

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Neutral

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Strongly Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

g) Conduct research into effects of nutrition and frailty

Second Priority

h) Determine cost-effectiveness of healthcare pathways

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approach to therapeutics

Second Priority

f) Support for high-risk projects

Third Priority

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Agree

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Strongly Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve understanding of disease mechanisms

Second Priority

a) Understand relationship between NDD and ageing

Third Priority

f) Focus research on rare hereditary forms of disease

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

a) Interactions between cells and their surrounding intra- and extracellular environment

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

At least animal models should be more scrutinized before being considered as representative models. There are several examples (e.g. in AD) where beneficial effects in animal models were not recapitulated in humans. Researchers and companies are too naive or move too fast in accepting a animal model as a representative model system. If more focus would be put on exploring the cellular models with respect to mechanistic insights one may also test more parameters in animal models and find out that after all they are not good models. Using AD again as an example, cellular models are in many cases used to evaluate if a certain compound, antibody or protein has an effect on Abeta production without having insights in any of the underlying mechanisms although the latter are needed to understand what these factors could do in an organism. Related to this, many questions in this section relate to genetic factors and how they interact: the reality should be that we need to emphasize the cell biology and study how their gene products interact, much more than the genes.

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Strongly Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Improve access to patient groups, samples and data

Second Priority

e) Develop centres of excellence

Third Priority

a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?

Convince researchers that excellence in research (and solving medical problems and physiological mechanisms) is the priority and not their CV and visibility. Decrease vanity and increase unconditional collaborations.

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

A problem is intellectual property and patenting: how many studies are being done in biotech companies without ever getting exposed to academia? Streamline rules on intellectual property at the international level.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

More resources go to less people; those who have high visibilities (through historical excellent research) will cluster more resources and thereby limiting resources for new talent or small labs with also big or brilliant ideas. It may widen the canyon or gap between the 'have's' and 'don't have's'. Another risk is that centers of excellence may define standards for others, may (because of their excellence) put more weight on decisionmakers or may drive research in preferred directions.

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Neutral

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Neutral

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

f) Review and update legislation on treatment

Strongly Agree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

c) Joint academic-industry funding models

Third Priority

d) Simplify funding application systems

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

- Little emphasis on basic molecular cell biology as a way to understand mechanisms of disease.

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Reserve funding for basic molecular cell biology without the (increasing) necessity to have clinical relevance or translational research included.

Question 3: Is there anything else you would like to tell us?

UID

1644

Category of respondee

Academic researcher - Clinical research

Country

France

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

d) Increase training for translational and clinician-scientists

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Disagree

b) Survey long-term care standards and provision across Europe

Neutral

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Neutral

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Neutral

g) Conduct research into effects of nutrition and frailty

Neutral

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

h) Determine cost-effectiveness of healthcare pathways

Second Priority

e) Rethink approaches to care

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Neutral

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

f) Support for high-risk projects

Third Priority

d) Ensure better patient selection/stratification

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Strongly Agree

e) Determine the importance of genetic and environmental risk factors

Strongly Agree

f) Focus research on rare hereditary forms of disease

Strongly Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve understanding of disease mechanisms

Second Priority

f) Focus research on rare hereditary forms of disease

Third Priority

d) Develop an improved understanding of the genetic basis

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Strongly Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Develop centres of excellence

Second Priority

a) Improve access to, and sharing of, infrastructure and resources

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Neutral

d) Encourage industry to adopt a pre-competitive approach to research

Strongly Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Strongly Agree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

d) Encourage industry to adopt pre-competitive approach

Second Priority

a) Need for evidence-based policy

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

a) Translational research needs to be promoted

Third Priority

c) Joint academic-industry funding models

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1645

Category of respondee

Academic researcher - Basic research

Country

France

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Neutral

c) Research into the needs of carers

Neutral

d) Research into care approaches including end of life decision-making

Neutral

e) Rethink approaches to care

Neutral

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

f) Understand and investigate influence of comorbidities on NDD

Second Priority

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Neutral

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

- e) Rethink approach to therapeutics
- f) Support for high-risk projects

Disagree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Increase involvement of individuals in research

Second Priority

- c) Conduct multi-centre primary prevention studies

Third Priority

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Strongly Agree

e) Determine the importance of genetic and environmental risk factors

Strongly Agree

f) Focus research on rare hereditary forms of disease

Strongly Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- f) Focus research on rare hereditary forms of disease

Second Priority

- d) Develop an improved understanding of the genetic basis

Third Priority

- h) Develop more representative animal and cell-based models

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

- c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

- c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Improve access to patient groups, samples and data

Second Priority

c) Improve data and sample collection

Third Priority

a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Neutral

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Disagree

d) Encourage industry to adopt a pre-competitive approach to research

e) Rethink patent lifetime and conduct public-private clinical trials

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Strongly Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

d) Simplify funding application systems

Third Priority

b) Encourage open-access sharing of data and materials

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1649

Category of respondee

Academic researcher - Clinical research

Country

France

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

c) Increase overall numbers of researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Strongly Agree

d) Research into care approaches including end of life decision-making

Strongly Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Disagree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Research into the needs of carers

Second Priority

e) Rethink approaches to care

Third Priority

b) Survey long-term care standards and provision across Europe

Question 3: How would you define "care"?

Provision of what is necessary for the health, welfare, maintenance, and protection of someone who is affected by a disease. The care is a multidisciplinary approach including physicians, social worker, psychologists, nurse and family members. Permanent exchanges between the team and adaptations are part of care definition - a personalized care should be our goal.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Care at home still relies on family members and this can be fragile in a long term construction. In order to promote care at home, we should make it easier for family members to do something by offering services or financial or material aid.

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

- a) **Increase involvement of individuals in research**
Strongly Agree
- b) **Promote development of non-pharmacological interventions**
Strongly Agree
- c) **Conduct multi-centre primary prevention studies**
Strongly Agree
- d) **Ensure better patient selection/stratification**
Disagree
- e) **Rethink approach to therapeutics**
Strongly Agree
- f) **Support for high-risk projects**
Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

- e) Rethink approach to therapeutics

Second Priority

- a) Increase involvement of individuals in research

Third Priority

- b) Promote development of non-pharmacological interventions

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Give more and early informations about (future) participation by care takers.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

If primary prevention strategies intend to avoid the development of disease we could focus on: - well defined genetic subgroups of carriers of NDD mutations to learn more about the development of first signs and onset - development of reliable biomarkers (including the presymptomatic phase)

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

- a) **Understand relationship between neurodegenerative disease and ageing**
Strongly Agree
- b) **Improve understanding of disease stages**
Agree
- c) **Improve understanding of disease mechanisms**
Strongly Agree
- d) **Develop an improved understanding of the genetic basis for NDD**
Strongly Agree
- e) **Determine the importance of genetic and environmental risk factors**
Strongly Agree
- f) **Focus research on rare hereditary forms of disease**
Strongly Agree
- g) **Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**
Agree
- h) **Develop more representative animal and cell-based models of disease**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- f) Focus research on rare hereditary forms of disease

Second Priority

- c) Improve understanding of disease mechanisms

Third Priority

- a) Understand relationship between NDD and ageing

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

- c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

No

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Strongly Agree

b) Redefine and harmonise clinical endpoints and outcomes

Strongly Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Strongly Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Agree

b) Improve access to patient groups, samples and data

Neutral

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Neutral

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Develop centres of excellence

Second Priority

c) Improve data and sample collection

Third Priority

a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?

Workshops and calls

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

data open access is useful

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

No

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Strongly Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Strongly Agree

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

f) Review and update legislation on treatment

Disagree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Need for evidence-based policy

Second Priority

e) Rethink patent lifetime and conduct public-private clinical trials

Third Priority

b) Ensure greater engagement with regulators

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) Translational research needs to be promoted**
Strongly Agree
- b) Encourage open-access sharing of data and materials**
Strongly Agree
- c) Joint academic-industry funding models**
Strongly Agree
- d) Simplify funding application systems**
Strongly Agree
- e) Maintain capacity for 'bottom-up' innovative funding**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Translational research needs to be promoted

Second Priority

- c) Joint academic-industry funding models

Third Priority

- d) Simplify funding application systems

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1653

Category of respondee

Academic researcher - Basic research

Country

France

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Neutral

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

research area out of the main streams

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

b) Survey long-term care standards and provision across Europe

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Neutral

c) Conduct multi-centre primary prevention studies

Strongly Agree

d) Ensure better patient selection/stratification

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

1) donation of brain material: by explaining to family that this is often the only way to make the diagnostic sure and that the material also help to validate results found in animals 2) increase the number of patient in research protocol : by explaining the advances made after each protocol

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Agree

e) Determine the importance of genetic and environmental risk factors

Strongly Agree

f) Focus research on rare hereditary forms of disease

Neutral

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Neutral

h) Develop more representative animal and cell-based models of disease

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve understanding of disease mechanisms

Second Priority

a) Understand relationship between NDD and ageing

Third Priority

b) Improve understanding of disease stages

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

a) Interactions between cells and their surrounding intra- and extracellular environment

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

1) human brain-bank (such as GIE-Neuroceb, Pr Charles Duyckaerts) collecting post-mortem brains from NDD patients and CONTROL PATIENTS is absolutely required and should be further supported and developed. The medical and pharmacological informations as well as the results of post-mortem anatomo-pathological should be accessible to researchers. 2) additional 'living' model (human cellular models, or mice non transgenic models reproducing pathological aging)

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Question 2: Which of the following do you think is most important in terms of biomarkers?

a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Strongly Agree

e) Develop centres of excellence

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Improve access to patient groups, samples and data

Second Priority

a) Improve access to, and sharing of, infrastructure and resources

Third Priority

d) Develop a register of persons with cognitive impairment

Question 3: What can be done to facilitate increased sharing of data?

free communications in all forms: free access publication, free webinars etc....

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

never exclude small group with original strategy of research concerning NDD

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Strongly Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Neutral

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Agree

f) Review and update legislation on treatment

Strongly Agree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Ensure greater engagement with regulators

Second Priority

f) Review and update legislation on treatment

Third Priority

e) Rethink patent lifetime and conduct public-private clinical trials

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Strongly Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Agree

e) Maintain capacity for 'bottom-up' innovative funding

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Encourage open-access sharing of data and materials

Second Priority

Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1720

Category of respondee

Academic researcher - Socio-economic or healthcare research

Country

Netherlands

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Question 2: If you had to choose one priority from the points above what would it be?

a) Improve dialogue between researchers and wider population

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Strongly Agree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Strongly Agree

g) Conduct research into effects of nutrition and frailty

Neutral

h) Determine cost-effectiveness of healthcare pathways

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

h) Determine cost-effectiveness of healthcare pathways

Second Priority

b) Survey long-term care standards and provision across Europe

Third Priority

c) Research into the needs of carers

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Neutral

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

b) Promote development of non-pharmacological interventions

Third Priority

d) Ensure better patient selection/stratification

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

b) Improve understanding of disease stages

c) Improve understanding of disease mechanisms

d) Develop an improved understanding of the genetic basis for NDD

e) Determine the importance of genetic and environmental risk factors

f) Focus research on rare hereditary forms of disease

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

h) Develop more representative animal and cell-based models of disease

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

b) Redefine and harmonise clinical endpoints and outcomes

c) Develop new biomarkers

d) Consider regulatory approaches

Question 2: Which of the following do you think is most important in terms of biomarkers?

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

b) Improve access to patient groups, samples and data

c) Improve data and sample collection

d) Develop a register of persons with cognitive impairment

e) Develop centres of excellence

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Agree

d) Encourage industry to adopt a pre-competitive approach to research

Neutral

e) Rethink patent lifetime and conduct public-private clinical trials

Neutral

f) Review and update legislation on treatment

Neutral

g) Review and update legislation on privacy and data disclosure

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Need for evidence-based policy

Second Priority

b) Ensure greater engagement with regulators

Third Priority

c) Facilitate research in areas outside university and hospital sectors

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Strongly Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Simplify funding application systems

Second Priority

a) Translational research needs to be promoted

Third Priority

e) Maintain capacity for 'bottom-up' innovative funding

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1722

Category of respondee

Academic researcher - Basic research

Country

Belgium

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

fundamental research in the drug discovery area

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Neutral

c) Research into the needs of carers

Neutral

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Neutral

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approaches to care

Second Priority

g) Conduct research into effects of nutrition and frailty

Third Priority

f) Understand and investigate influence of comorbidities on NDD

Question 3: How would you define "care"?

to provide help and assistance to people with a disease or disability

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

no

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

-

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

f) Support for high-risk projects

Second Priority

e) Rethink approach to therapeutics

Third Priority

b) Promote development of non-pharmacological interventions

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

better communication about the need for the studies and the risks

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

food stress factors

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Strongly Agree

e) Determine the importance of genetic and environmental risk factors

Strongly Agree

f) Focus research on rare hereditary forms of disease

Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve understanding of disease mechanisms

Second Priority

h) Develop more representative animal and cell-based models

Third Priority

b) Improve understanding of disease stages

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

I don't know

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Neutral

e) Develop centres of excellence

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Improve access to, and sharing of, infrastructure and resources

Second Priority

b) Improve access to patient groups, samples and data

Third Priority

e) Develop centres of excellence

Question 3: What can be done to facilitate increased sharing of data?

public-private partnerships

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

-

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

not really

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Neutral

b) Ensure greater engagement with regulators

Neutral

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Agree

d) Encourage industry to adopt a pre-competitive approach to research

Disagree

e) Rethink patent lifetime and conduct public-private clinical trials

Agree

f) Review and update legislation on treatment

Neutral

g) Review and update legislation on privacy and data disclosure

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink patent lifetime and conduct public-private clinical trials

Second Priority

c) Facilitate research in areas outside university and hospital sectors

Third Priority

a) Need for evidence-based policy

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

no

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) **Translational research needs to be promoted**
Agree
- b) **Encourage open-access sharing of data and materials**
Agree
- c) **Joint academic-industry funding models**
Strongly Agree
- d) **Simplify funding application systems**
Strongly Agree
- e) **Maintain capacity for 'bottom-up' innovative funding**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- c) Joint academic-industry funding models

Second Priority

- e) Maintain capacity for 'bottom-up' innovative funding

Third Priority

- d) Simplify funding application systems

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

no experience

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

-

Question 2: Do you have any comments on how to implement the above suggestion(s)?

-

Question 3: Is there anything else you would like to tell us?

In the Netherlands we have TI Pharma, a public-private partnership between government, industry and universities. As far as I can see this approach worked quite well, and might be implemented in other countries or Europe as well.

UID

1753

Category of respondee

Academic researcher - Socio-economic or healthcare research

Country

United Kingdom

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Neutral

d) Increase training for translational and clinician-scientists

Neutral

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Strongly Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Strongly Agree

h) Determine cost-effectiveness of healthcare pathways

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approaches to care

Second Priority

c) Research into the needs of carers

Third Priority

g) Conduct research into effects of nutrition and frailty

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Neutral

b) Promote development of non-pharmacological interventions

Strongly Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approach to therapeutics

Second Priority

b) Promote development of non-pharmacological interventions

Third Priority

f) Support for high-risk projects

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Agree

d) Develop an improved understanding of the genetic basis for NDD

Neutral

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Disagree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

g) Establish pan-European population-based studies

Second Priority

e) Determine the importance of genetic and environmental risk factors

Third Priority

h) Develop more representative animal and cell-based models

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Neutral

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Neutral

b) Improve access to patient groups, samples and data

Neutral

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Neutral

e) Develop centres of excellence

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve data and sample collection

Second Priority

e) Develop centres of excellence

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Strongly Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Strongly Agree

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Agree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Facilitate research in areas outside university and hospital sectors

Second Priority

g) Review and update legislation on privacy and data disclosure

Third Priority

a) Need for evidence-based policy

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Neutral

c) Joint academic-industry funding models

Neutral

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

d) Simplify funding application systems

Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1759

Category of respondee

Academic researcher - Basic research

Country

France

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Neutral

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

b) Survey long-term care standards and provision across Europe

c) Research into the needs of carers

d) Research into care approaches including end of life decision-making

e) Rethink approaches to care

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Neutral

h) Determine cost-effectiveness of healthcare pathways

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Disagree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Strongly Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- f) Support for high-risk projects

Second Priority

- d) Ensure better patient selection/stratification

Third Priority

- a) Increase involvement of individuals in research

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Agree

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Neutral

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Neutral

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- c) Improve understanding of disease mechanisms

Second Priority

- h) Develop more representative animal and cell-based models

Third Priority

- a) Understand relationship between NDD and ageing

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

- b) Neuronal inflammation

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

- a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Disagree

e) Develop centres of excellence

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Improve access to patient groups, samples and data

Second Priority

e) Develop centres of excellence

Third Priority

a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

b) Ensure greater engagement with regulators

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

f) Review and update legislation on treatment

g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Neutral

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Simplify funding application systems

Second Priority

e) Maintain capacity for 'bottom-up' innovative funding

Third Priority

a) Translational research needs to be promoted

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1760

Category of respondee

Academic researcher - Socio-economic or healthcare research

Country

United Kingdom

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Neutral

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

b) Improve education and training of healthcare professionals

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Strongly Agree

c) Research into the needs of carers

Neutral

d) Research into care approaches including end of life decision-making

Strongly Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

h) Determine cost-effectiveness of healthcare pathways

Second Priority

e) Rethink approaches to care

Third Priority

d) Research end of life decision making

Question 3: How would you define "care"?

Support and interventions needed to maintain a person's well being and quality of life

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Funding of more rigorous evaluation of local models of best practice

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Not sure

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

- b) **Promote development of non-pharmacological interventions**
Strongly Agree
- c) **Conduct multi-centre primary prevention studies**
Strongly Agree
- d) **Ensure better patient selection/stratification**
Agree
- e) **Rethink approach to therapeutics**
Strongly Agree
- f) **Support for high-risk projects**
Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- c) Conduct multi-centre primary prevention studies

Second Priority

- b) Promote development of non-pharmacological interventions

Third Priority

- e) Rethink approach to therapeutics

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Educate GPs/nurses ie health professionals on the ground and those in charge of the care of most older people

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Tight control of BP Exercise

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

- a) **Understand relationship between neurodegenerative disease and ageing**
Strongly Agree
- b) **Improve understanding of disease stages**
Strongly Agree
- c) **Improve understanding of disease mechanisms**
Agree
- d) **Develop an improved understanding of the genetic basis for NDD**
Agree
- e) **Determine the importance of genetic and environmental risk factors**
Neutral
- f) **Focus research on rare hereditary forms of disease**
Disagree
- g) **Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**
Strongly Agree
- h) **Develop more representative animal and cell-based models of disease**
Disagree

Question 2: Please rank the suggestions in order of priority

First Priority

- g) Establish pan-European population-based studies

Second Priority

- a) Understand relationship between NDD and ageing

Third Priority

- b) Improve understanding of disease stages

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

b) Neuronal inflammation

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

I am sorry but this is not my area at all and so do not feel qualified to comment knowledgeably.

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

- a) **Redefine and standardise disease definitions and diagnosis**
Agree
- b) **Redefine and harmonise clinical endpoints and outcomes**

Neutral

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Strongly Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Improve access to, and sharing of, infrastructure and resources

Second Priority

e) Develop centres of excellence

Third Priority

d) Develop a register of persons with cognitive impairment

Question 3: What can be done to facilitate increased sharing of data?

Compulsory use of data sharing agreements as part of funder agreements when research funding is awarded.

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

I am entirely in favour of this; however it would be helpful to have a standard approved agreement document that researchers could use instead of drafting up a new one.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Yes - such centres must not be just academic centres of research excellence; there must be a combined focus on translational research, to inform service provision, and linked training centres to facilitate the creation of a skilled and motivated workforce. The recent report from the UK-ILC highlights the need for centres of excellence greater than just research!

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Neutral

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Strongly Agree

d) Encourage industry to adopt a pre-competitive approach to research

Neutral

e) Rethink patent lifetime and conduct public-private clinical trials

Disagree

f) Review and update legislation on treatment

Neutral

g) Review and update legislation on privacy and data disclosure

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

c) Facilitate research in areas outside university and hospital sectors

Second Priority

a) Need for evidence-based policy

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Sorry not off the top of my head!

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Strongly Agree

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Translational research needs to be promoted

Second Priority

c) Joint academic-industry funding models

Third Priority

d) Simplify funding application systems

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

We need to rethinking the balance of research funding awarded - currently in dementia, more is allocated to finding cause and cure, rather than looking at cost-effective models of care. In addition, the current funding system in the UK is potentially inhibitory to research into innovative care models with the system of calculating NHS extra treatment costs in addition to research costs. The latter are potentially very high and I have personal experience of much needed research being prevented because the NIHR funded stated the NHS treatment costs were too high, even though they approved the research costs and had agreed to fund the project.

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1781

Category of respondee

Academic researcher - Clinical research

Country

Norway

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Neutral

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Neutral

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Research into the needs of carers

Second Priority

e) Rethink approaches to care

Third Priority

h) Determine cost-effectiveness of healthcare pathways

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Agree

d) **Ensure better patient selection/stratification**

Agree

e) **Rethink approach to therapeutics**

Agree

f) **Support for high-risk projects**

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) **Understand relationship between neurodegenerative disease and ageing**

Strongly Agree

b) **Improve understanding of disease stages**

Strongly Agree

c) **Improve understanding of disease mechanisms**

Strongly Agree

d) **Develop an improved understanding of the genetic basis for NDD**

Agree

e) **Determine the importance of genetic and environmental risk factors**

Agree

f) **Focus research on rare hereditary forms of disease**

Neutral

g) **Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**

Neutral

h) **Develop more representative animal and cell-based models of disease**

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve understanding of disease mechanisms

Second Priority

h) Develop more representative animal and cell-based models

Third Priority

a) Understand relationship between NDD and ageing

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) **Redefine and standardise disease definitions and diagnosis**

Agree

b) **Redefine and harmonise clinical endpoints and outcomes**

Strongly Agree

c) **Develop new biomarkers**

Strongly Agree

d) **Consider regulatory approaches**

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Neutral

e) Develop centres of excellence

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Improve access to patient groups, samples and data

Second Priority

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Disagree

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Neutral

f) Review and update legislation on treatment

Neutral

g) Review and update legislation on privacy and data disclosure

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Neutral

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Simplify funding application systems

Second Priority
Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1782

Category of respondee

Academic researcher - Clinical research

Country

France

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

c) Increase overall numbers of researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Strongly Agree

g) Conduct research into effects of nutrition and frailty

Strongly Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

f) Understand and investigate influence of comorbidities on NDD

Second Priority

g) Conduct research into effects of nutrition and frailty

Third Priority

b) Survey long-term care standards and provision across Europe

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Strongly Agree

d) Ensure better patient selection/stratification

Strongly Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

c) Conduct multi-centre primary prevention studies

Third Priority

f) Support for high-risk projects

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Agree

d) Develop an improved understanding of the genetic basis for NDD

Agree

e) Determine the importance of genetic and environmental risk factors

Strongly Agree

f) Focus research on rare hereditary forms of disease

Neutral

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Strongly Agree

h) Develop more representative animal and cell-based models of disease

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Determine the importance of genetic and environmental risk factors

Second Priority

a) Understand relationship between NDD and ageing

Third Priority

c) Improve understanding of disease mechanisms

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

d) The biological basis of behavioural and psychological symptoms

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Strongly Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

b) Linking to treatment responses

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Improve access to, and sharing of, infrastructure and resources

Second Priority

b) Improve access to patient groups, samples and data

Third Priority

c) Improve data and sample collection

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Neutral

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Disagree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Need for evidence-based policy

Second Priority

b) Ensure greater engagement with regulators

Third Priority

f) Review and update legislation on treatment

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Strongly Agree

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Translational research needs to be promoted

Second Priority

b) Encourage open-access sharing of data and materials

Third Priority

c) Joint academic-industry funding models

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1786

Category of respondee

Academic researcher - Basic research

Country

Belgium

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Neutral

b) Improve education and training of healthcare professionals

Neutral

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Neutral

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

There is a need for increased financing possibilities for and recognition of international collaboration in areas where this is key to success.

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Neutral

c) Research into the needs of carers

Neutral

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approaches to care

Second Priority

f) Understand and investigate influence of comorbidities on NDD

Third Priority

h) Determine cost-effectiveness of healthcare pathways

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Strongly Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

d) Ensure better patient selection/stratification

Third Priority

e) Rethink approach to therapeutics

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

By financing dedicated staff such as research nurses and clinical scientists. This human, personal communication is I believe key in getting patients to participate as well as getting the accurate information that are crucial for such studies.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Strongly Agree

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Strongly Disagree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Strongly Agree

h) Develop more representative animal and cell-based models of disease

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

d) Develop an improved understanding of the genetic basis

Second Priority

c) Improve understanding of disease mechanisms

Third Priority

g) Establish pan-European population-based studies

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

b) Neuronal inflammation

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Strongly Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Disagree

Question 2: Which of the following do you think is most important in terms of biomarkers?

a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Neutral

e) Develop centres of excellence

Disagree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Improve access to patient groups, samples and data

Second Priority

c) Improve data and sample collection

Third Priority

a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

b) Ensure greater engagement with regulators

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

d) Encourage industry to adopt a pre-competitive approach to research

e) Rethink patent lifetime and conduct public-private clinical trials

f) Review and update legislation on treatment

g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

b) Encourage open-access sharing of data and materials

c) Joint academic-industry funding models

d) Simplify funding application systems

e) Maintain capacity for 'bottom-up' innovative funding

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1851

Category of respondent

Academic researcher - Clinical research

Country

United Kingdom

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

d) Increase training for translational and clinician-scientists

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Strongly Agree

c) Research into the needs of carers

Strongly Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

f) Understand and investigate influence of comorbidities on NDD

Second Priority

c) Research into the needs of carers

Third Priority

g) Conduct research into effects of nutrition and frailty

Question 3: How would you define "care"?

Providing psychological, social and medical support and treatment for the disease and effects of disease on patient and carer

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Increase the availability of respite care and carer support

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

- b) **Promote development of non-pharmacological interventions**
Strongly Agree
- c) **Conduct multi-centre primary prevention studies**
Neutral
- d) **Ensure better patient selection/stratification**
Strongly Agree
- e) **Rethink approach to therapeutics**
Strongly Agree
- f) **Support for high-risk projects**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- d) Ensure better patient selection/stratification

Second Priority

- a) Increase involvement of individuals in research

Third Priority

- e) Rethink approach to therapeutics

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Provide time and support for clinicians outside specialist to centres, particularly providing support and training for nurse specialists

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

I do not think we are necessarily in that position but trials of agents that modify the vascular and inflammatory response in AD, and mitochondrial function in early onset PD could be considered

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

- a) **Understand relationship between neurodegenerative disease and ageing**
Strongly Agree
- b) **Improve understanding of disease stages**
Agree
- c) **Improve understanding of disease mechanisms**
Agree
- d) **Develop an improved understanding of the genetic basis for NDD**
Agree
- e) **Determine the importance of genetic and environmental risk factors**
Neutral
- f) **Focus research on rare hereditary forms of disease**
Strongly Agree
- g) **Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**
Strongly Agree
- h) **Develop more representative animal and cell-based models of disease**

Question 2: Please rank the suggestions in order of priority

First Priority

- b) Improve understanding of disease stages

Second Priority

- f) Focus research on rare hereditary forms of disease

Third Priority

- d) Develop an improved understanding of the genetic basis

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

- c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Yes - for rapidly progressive neurodegenerative diseases like MND

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

- a) **Redefine and standardise disease definitions and diagnosis**
Neutral
- b) **Redefine and harmonise clinical endpoints and outcomes**

Strongly Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve data and sample collection

Second Priority

a) Improve access to, and sharing of, infrastructure and resources

Third Priority

e) Develop centres of excellence

Question 3: What can be done to facilitate increased sharing of data?

provide funding for collection of data and samples as supplementary to other studies

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

support

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

need to be linked with networks 'outside' the centre

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Agree

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Strongly Agree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink patent lifetime and conduct public-private clinical trials

Second Priority

a) Need for evidence-based policy

Third Priority

d) Encourage industry to adopt pre-competitive approach

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) **Translational research needs to be promoted**
Agree
- b) **Encourage open-access sharing of data and materials**
Agree
- c) **Joint academic-industry funding models**
Agree
- d) **Simplify funding application systems**
Agree
- e) **Maintain capacity for 'bottom-up' innovative funding**
Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Translational research needs to be promoted

Second Priority

- c) Joint academic-industry funding models

Third Priority

- d) Simplify funding application systems

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

No

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1881

Category of respondee

Academic researcher - Clinical research

Country

Spain

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Human sciences as Psychology

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Strongly Agree

c) Research into the needs of carers

Neutral

d) Research into care approaches including end of life decision-making

Strongly Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Research end of life decision making

Second Priority

e) Rethink approaches to care

Third Priority

b) Survey long-term care standards and provision across Europe

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Strongly Agree

c) Conduct multi-centre primary prevention studies

Strongly Agree

d) Ensure better patient selection/stratification

Strongly Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Promote development of non-pharmacological interventions

Second Priority

c) Conduct multi-centre primary prevention studies

Third Priority

e) Rethink approach to therapeutics

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Neutral

d) Develop an improved understanding of the genetic basis for NDD

Neutral

e) Determine the importance of genetic and environmental risk factors

Neutral

f) Focus research on rare hereditary forms of disease

Neutral

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Neutral

h) Develop more representative animal and cell-based models of disease

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

b) Improve understanding of disease stages

Second Priority

a) Understand relationship between NDD and ageing

Third Priority

g) Establish pan-European population-based studies

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

d) The biological basis of behavioural and psychological symptoms

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Strongly Agree

b) Redefine and harmonise clinical endpoints and outcomes

Strongly Agree

c) Develop new biomarkers

Neutral

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

- c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Strongly Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- e) Develop centres of excellence

Second Priority

- a) Improve access to, and sharing of, infrastructure and resources

Third Priority

- b) Improve access to patient groups, samples and data

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Neutral

b) Ensure greater engagement with regulators

Neutral

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Strongly Agree

d) Encourage industry to adopt a pre-competitive approach to research

Neutral

e) Rethink patent lifetime and conduct public-private clinical trials

Agree

f) Review and update legislation on treatment

Neutral

g) Review and update legislation on privacy and data disclosure

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

- c) Facilitate research in areas outside university and hospital sectors

Second Priority

- e) Rethink patent lifetime and conduct public-private clinical trials

Third Priority

- f) Review and update legislation on treatment

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Simplify funding application systems

Second Priority

c) Joint academic-industry funding models

Third Priority

e) Maintain capacity for 'bottom-up' innovative funding

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1905

Category of respondee

Academic researcher - Clinical research

Country

Ireland

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Neutral

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

a) Improve dialogue between researchers and wider population

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Make people aware that cognitive impairments with older age are not a "normal" component of older age.

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

b) Survey long-term care standards and provision across Europe

c) Research into the needs of carers

d) Research into care approaches including end of life decision-making

e) Rethink approaches to care

f) Understand and investigate influence of comorbidities

g) Conduct research into effects of nutrition and frailty

h) Determine cost-effectiveness of healthcare pathways

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Strongly Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Increase involvement of individuals in research

Second Priority

- b) Promote development of non-pharmacological interventions

Third Priority

- c) Conduct multi-centre primary prevention studies

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Better education and information for older people. In addition, training for registrars in explaining the purpose of research and the value that it brings to health care.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

I don't think we have reached this stage.

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Agree

d) Develop an improved understanding of the genetic basis for NDD

Neutral

e) Determine the importance of genetic and environmental risk factors

Neutral

f) Focus research on rare hereditary forms of disease

Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Understand relationship between NDD and ageing

Second Priority

- b) Improve understanding of disease stages

Third Priority

- g) Establish pan-European population-based studies

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

- c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Strongly Agree

b) Redefine and harmonise clinical endpoints and outcomes

Neutral

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

- a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

- a) **Improve access to, and sharing of, infrastructure and resources**
Strongly Agree
- b) **Improve access to patient groups, samples and data**
Strongly Agree
- c) **Improve data and sample collection**
Agree
- d) **Develop a register of persons with cognitive impairment**
Neutral
- e) **Develop centres of excellence**
Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

- b) Improve access to patient groups, samples and data

Second Priority

- c) Improve data and sample collection

Third Priority

- a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?

The key is that researchers/groups should receive funding for acquisition of data and hence the motivation from the beginning is to develop the database that the wider community would avail. One model is the US-ADNI where the data acquisition was financed and the data has been available to all for analysis.

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

There will be issues of privacy and making sure that the data is not misused but I don't think they are major problems. The evidence from the USA, Australia and European multicentre studies (outside of NDD) have demonstrated that this is not a major difficulty.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Yes, as skilled researchers may be shut out of performing research. Also new ideas or concepts may not be developed in favor of more safe approaches to investigating NDD.

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) **Need for evidence-based policy**

Agree

b) **Ensure greater engagement with regulators**

Agree

c) **Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**

Agree

d) **Encourage industry to adopt a pre-competitive approach to research**

Agree

e) **Rethink patent lifetime and conduct public-private clinical trials**

Neutral

f) **Review and update legislation on treatment**

Strongly Agree

g) **Review and update legislation on privacy and data disclosure**

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Need for evidence-based policy

Second Priority

- d) Encourage industry to adopt pre-competitive approach

Third Priority

- c) Facilitate research in areas outside university and hospital sectors

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) **Translational research needs to be promoted**

Agree

b) **Encourage open-access sharing of data and materials**

Agree

c) **Joint academic-industry funding models**

Agree

d) Simplify funding application systems

Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

b) Encourage open-access sharing of data and materials

Third Priority

c) Joint academic-industry funding models

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Establishing an electronic database for accessing data for european studies on NDD.

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1908

Category of respondent

Academic researcher - Basic research

Country

United Kingdom

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

c) Increase overall numbers of researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

No

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Neutral

c) Research into the needs of carers

Neutral

d) Research into care approaches including end of life decision-making

Neutral

e) Rethink approaches to care

Neutral

f) Understand and investigate influence of comorbidities

Neutral

g) Conduct research into effects of nutrition and frailty

Neutral

h) Determine cost-effectiveness of healthcare pathways

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Neutral

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Strongly Agree

e) Determine the importance of genetic and environmental risk factors

Strongly Agree

f) Focus research on rare hereditary forms of disease

Disagree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve understanding of disease mechanisms

Second Priority

h) Develop more representative animal and cell-based models

Third Priority

e) Determine the importance of genetic and environmental risk factors

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

a) Interactions between cells and their surrounding intra- and extracellular environment

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Neutral

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Strongly Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Develop centres of excellence

Second Priority

a) Improve access to, and sharing of, infrastructure and resources

Third Priority

b) Improve access to patient groups, samples and data

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Resources may become concentrated and individual researchers not part of the centres, but nonetheless doing valuable work, might be less able to gain support.

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Strongly Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Neutral

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Neutral

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Need for evidence-based policy

Second Priority

b) Ensure greater engagement with regulators

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Neutral

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

d) Simplify funding application systems

Third Priority

a) Translational research needs to be promoted

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1912

Category of respondee

Academic researcher - Basic research

Country

United States

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Disagree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Disagree

Question 2: If you had to choose one priority from the points above what would it be?

a) Improve dialogue between researchers and wider population

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

b) Survey long-term care standards and provision across Europe

c) Research into the needs of carers

d) Research into care approaches including end of life decision-making

e) Rethink approaches to care

f) Understand and investigate influence of comorbidities

g) Conduct research into effects of nutrition and frailty

h) Determine cost-effectiveness of healthcare pathways

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

b) Promote development of non-pharmacological interventions

c) Conduct multi-centre primary prevention studies

d) Ensure better patient selection/stratification

e) Rethink approach to therapeutics

f) Support for high-risk projects

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

- a) **Understand relationship between neurodegenerative disease and ageing**
Strongly Agree
- b) **Improve understanding of disease stages**
Neutral
- c) **Improve understanding of disease mechanisms**
Strongly Agree
- d) **Develop an improved understanding of the genetic basis for NDD**
Strongly Agree
- e) **Determine the importance of genetic and environmental risk factors**
Strongly Agree
- f) **Focus research on rare hereditary forms of disease**
Neutral
- g) **Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**
Strongly Agree
- h) **Develop more representative animal and cell-based models of disease**
Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- c) Improve understanding of disease mechanisms

Second Priority

- a) Understand relationship between NDD and ageing

Third Priority

- d) Develop an improved understanding of the genetic basis

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

- d) The biological basis of behavioural and psychological symptoms

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

No

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

- a) **Redefine and standardise disease definitions and diagnosis**
Agree
- b) **Redefine and harmonise clinical endpoints and outcomes**
Agree
- c) **Develop new biomarkers**
Strongly Agree
- d) **Consider regulatory approaches**
Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

- c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

- a) **Improve access to, and sharing of, infrastructure and resources**
Strongly Agree
- b) **Improve access to patient groups, samples and data**
Strongly Agree
- c) **Improve data and sample collection**
Agree
- d) **Develop a register of persons with cognitive impairment**
Agree
- e) **Develop centres of excellence**
Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Improve access to, and sharing of, infrastructure and resources

Second Priority

- b) Improve access to patient groups, samples and data

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

- a) Need for evidence-based policy
- b) Ensure greater engagement with regulators
- c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community
- d) Encourage industry to adopt a pre-competitive approach to research
- e) Rethink patent lifetime and conduct public-private clinical trials
- f) Review and update legislation on treatment
- g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) Translational research needs to be promoted
- b) Encourage open-access sharing of data and materials
- c) Joint academic-industry funding models
- d) Simplify funding application systems
- e) Maintain capacity for 'bottom-up' innovative funding

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1915

Category of respondee

Academic researcher - Socio-economic or healthcare research

Country

Germany

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Neutral

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

d) Increase training for translational and clinician-scientists

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health care research especially in the primary care setting as this is the most realistic setting to learn, how health care is being performed.

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Strongly Agree

b) Survey long-term care standards and provision across Europe

Strongly Agree

c) Research into the needs of carers

Strongly Agree

d) Research into care approaches including end of life decision-making

Strongly Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Strongly Agree

g) Conduct research into effects of nutrition and frailty

Strongly Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Define the term 'care'

Second Priority

b) Survey long-term care standards and provision across Europe

Third Priority

e) Rethink approaches to care

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Money drives the way health care providers work. In my eyes the reimbursement systems are too complicated in many countries, especially in Germany. I think that the reimbursement system must be taken into account when doing research on care standards and provision - and trying to improve them.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

I don't think that we have to promote the advantages. Most of the elderly do want to stay at home as long as this is possible. Besides care support one reason why people can't stay at home any more is loneliness. So community initiatives in order to foster contacts might be of importance.

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

- a) **Increase involvement of individuals in research**
Neutral
- b) **Promote development of non-pharmacological interventions**
Strongly Agree
- c) **Conduct multi-centre primary prevention studies**
Strongly Agree
- d) **Ensure better patient selection/stratification**
Strongly Disagree
- e) **Rethink approach to therapeutics**
Strongly Agree
- f) **Support for high-risk projects**
Strongly Disagree

Question 2: Please rank the suggestions in order of priority

First Priority

- b) Promote development of non-pharmacological interventions

Second Priority

- c) Conduct multi-centre primary prevention studies

Third Priority

- e) Rethink approach to therapeutics

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Good public campaigns.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

first of all: physical exercise, social contact and intellectual challenge through community involvement or work, and also: the common medical parameters like blood pressure, lipid status, obesity and the common lifestyle factors like smoking, alcohol and nutrition.

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

- a) **Understand relationship between neurodegenerative disease and ageing**
Strongly Disagree
- b) **Improve understanding of disease stages**
Strongly Agree
- c) **Improve understanding of disease mechanisms**
Strongly Disagree
- d) **Develop an improved understanding of the genetic basis for NDD**
Strongly Disagree
- e) **Determine the importance of genetic and environmental risk factors**
Strongly Disagree
- f) **Focus research on rare hereditary forms of disease**
Strongly Disagree
- g) **Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**
Neutral
- h) **Develop more representative animal and cell-based models of disease**
Strongly Disagree

Question 2: Please rank the suggestions in order of priority

First Priority

- b) Improve understanding of disease stages

Second Priority

Third Priority

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

No.

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

- a) **Redefine and standardise disease definitions and diagnosis**
Agree
- b) **Redefine and harmonise clinical endpoints and outcomes**
Strongly Agree
- c) **Develop new biomarkers**
Strongly Disagree
- d) **Consider regulatory approaches**
Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

- a) **Improve access to, and sharing of, infrastructure and resources**
Strongly Agree
- b) **Improve access to patient groups, samples and data**
Strongly Disagree
- c) **Improve data and sample collection**
Strongly Disagree
- d) **Develop a register of persons with cognitive impairment**
Strongly Disagree
- e) **Develop centres of excellence**
Strongly Disagree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Improve access to, and sharing of, infrastructure and resources

Second Priority

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Sharing of data sounds good but is difficult in reality because of many reasons: - those who have performed a study are interested in analysis and publication themselves - those who were not involved in the study procedures often don't get a clear picture how data have been collected exactly and how study procedures were. This is especially the case for longitudinal studies in which SOPs change over time. Analysis of data that are not completely well known may lead to false results. - Scientists often get funding for the performing of a study and collection of data. It often lacks a follow-up financing for data analysis and publication. Funding should also target this step of research. Analysing and writing of a good paper can take up to six months.

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

See my answer to the question above. If data are to be made open access an unmistakable description of each variable and the way of data collection has to be made. Dependent on the amount of data this step is a project itself and needs funding.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Yes. Centres of excellence require too much money for infrastructure. Once they are established, it is difficult to close them again even if their research results are not satisfactory because of all the money already spent. So the risk of investments in such centres is much higher than the risk of investments in single research projects. That's why I prefer funding of single research projects. It is possible to perform huge, longitudinal multi-center trials with a group of universities as long as funding is assured.

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

- a) **Need for evidence-based policy**
Strongly Agree
- b) **Ensure greater engagement with regulators**
Neutral
- c) **Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**
Strongly Agree
- d) **Encourage industry to adopt a pre-competitive approach to research**
Strongly Disagree
- e) **Rethink patent lifetime and conduct public-private clinical trials**
Strongly Disagree
- f) **Review and update legislation on treatment**
Neutral
- g) **Review and update legislation on privacy and data disclosure**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Need for evidence-based policy

Second Priority

g) Review and update legislation on privacy and data disclosure

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Neutral

b) Encourage open-access sharing of data and materials

Neutral

c) Joint academic-industry funding models

Strongly Disagree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Simplify funding application systems

Second Priority

e) Maintain capacity for 'bottom-up' innovative funding

Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1942

Category of respondee

Academic researcher - Basic research

Country

United Kingdom

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Neutral

Question 2: If you had to choose one priority from the points above what would it be?

d) Increase training for translational and clinician-scientists

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Multidisciplinary working between computing, engineering, chemistry, physics and the medical and biology disciplines.

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Strongly Agree

d) Research into care approaches including end of life decision-making

Strongly Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approaches to care

Second Priority

e) Rethink approaches to care

Third Priority

g) Conduct research into effects of nutrition and frailty

Question 3: How would you define "care"?

Looking after people to maintain a high quality of life as is possible preferably at home

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Better communication. Many families do not know what is available

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Strongly Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

e) Rethink approach to therapeutics

Third Priority

c) Conduct multi-centre primary prevention studies

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Better communication about the benefits and making donating easier.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Agree

e) Determine the importance of genetic and environmental risk factors

Strongly Agree

f) Focus research on rare hereditary forms of disease

Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Strongly Agree

h) Develop more representative animal and cell-based models of disease

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve understanding of disease mechanisms

Second Priority

g) Establish pan-European population-based studies

Third Priority

e) Determine the importance of genetic and environmental risk factors

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Where there is no safety issue and the animal models give no relevant read out of information. (ie need animals for tox but nothing else)

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Strongly Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

- c) **Develop new biomarkers**
Strongly Agree
- d) **Consider regulatory approaches**
Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?
d) Facilitating back-translation to models of disease

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

- a) **Improve access to, and sharing of, infrastructure and resources**
Strongly Agree
- b) **Improve access to patient groups, samples and data**
Strongly Agree
- c) **Improve data and sample collection**
Agree
- d) **Develop a register of persons with cognitive impairment**
Agree
- e) **Develop centres of excellence**
Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Improve access to, and sharing of, infrastructure and resources

Second Priority

- b) Improve access to patient groups, samples and data

Third Priority

- e) Develop centres of excellence

Question 3: What can be done to facilitate increased sharing of data?

Make funding dependent on it and make partnerships with funders to minimise duplication

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

This is working better now and should improve further if the funders remain committed to it.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

They stagnate unless they are multicentre and not building based. Need evaluation of leaders and ideas

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

- a) **Need for evidence-based policy**
Strongly Agree
- b) **Ensure greater engagement with regulators**
Agree
- c) **Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**
Agree
- d) **Encourage industry to adopt a pre-competitive approach to research**
Strongly Agree
- e) **Rethink patent lifetime and conduct public-private clinical trials**
Agree
- f) **Review and update legislation on treatment**
Strongly Agree
- g) **Review and update legislation on privacy and data disclosure**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- g) Review and update legislation on privacy and data disclosure

Second Priority

- e) Rethink patent lifetime and conduct public-private clinical trials

Third Priority

- a) Need for evidence-based policy

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Strongly Agree

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

c) Joint academic-industry funding models

Third Priority

b) Encourage open-access sharing of data and materials

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Engage funders in promoting this.

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1969

Category of respondee

Academic researcher - Socio-economic or healthcare research

Country

Netherlands

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

d) Increase training for translational and clinician-scientists

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

knowledge on psychosocial interventions of clinicians

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Disagree

b) Survey long-term care standards and provision across Europe

Disagree

c) Research into the needs of carers

Strongly Agree

d) Research into care approaches including end of life decision-making

Strongly Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Research into the needs of carers

Second Priority

e) Rethink approaches to care

Third Priority

d) Research end of life decision making

Question 3: How would you define "care"?

Actions supposed to be supportive in a practical emotional, or social way. It should be person centered: on the whole person, not on the diseased brain remaining abilities, not only on losses within the family and cultural context centered within a wide society and its values

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

By prioritising attention for autonomy, dignity and reciprocity

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

support the carers and provide person centered care both for patients and carers

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Strongly Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Strongly Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Promote development of non-pharmacological interventions

Second Priority

d) Ensure better patient selection/stratification

Third Priority

e) Rethink approach to therapeutics

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Neutral

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Neutral

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Improve understanding of disease stages

Second Priority

a) Understand relationship between NDD and ageing

Third Priority

c) Improve understanding of disease mechanisms

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

d) The biological basis of behavioural and psychological symptoms

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Disagree

e) Develop centres of excellence

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Improve access to, and sharing of, infrastructure and resources

Second Priority

c) Improve data and sample collection

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

too much concentration on one topic access to patient population (recruitment problems) wide variety of expertise needed in dementia research, variety of centres needed to provide this expertise too much centred on few and large communities

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Strongly Agree

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Neutral

f) Review and update legislation on treatment

Strongly Agree

g) Review and update legislation on privacy and data disclosure

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Facilitate research in areas outside university and hospital sectors

Second Priority

a) Need for evidence-based policy

Third Priority

g) Review and update legislation on privacy and data disclosure

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Agree

e) Maintain capacity for 'bottom-up' innovative funding

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1994

Category of respondee

Academic researcher - Socio-economic or healthcare research

Country

Germany

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Neutral

e) Increase numbers of post-doctoral level researchers

Neutral

Question 2: If you had to choose one priority from the points above what would it be?

b) Improve education and training of healthcare professionals

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Strongly Agree

c) Research into the needs of carers

Strongly Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Neutral

g) Conduct research into effects of nutrition and frailty

Neutral

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approaches to care

Second Priority

c) Research into the needs of carers

Third Priority

b) Survey long-term care standards and provision across Europe

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Strongly Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Neutral

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

b) Promote development of non-pharmacological interventions

Second Priority

a) Increase involvement of individuals in research

Third Priority

c) Conduct multi-centre primary prevention studies

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

- a) Understand relationship between neurodegenerative disease and ageing
- b) Improve understanding of disease stages
- c) Improve understanding of disease mechanisms
- d) Develop an improved understanding of the genetic basis for NDD
- e) Determine the importance of genetic and environmental risk factors
- f) Focus research on rare hereditary forms of disease
- g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups
- h) Develop more representative animal and cell-based models of disease

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

- a) Redefine and standardise disease definitions and diagnosis
- b) Redefine and harmonise clinical endpoints and outcomes
- c) Develop new biomarkers
- d) Consider regulatory approaches

Question 2: Which of the following do you think is most important in terms of biomarkers?

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Agree

b) Improve access to patient groups, samples and data

c) Improve data and sample collection

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Strongly Agree

d) Encourage industry to adopt a pre-competitive approach to research

e) Rethink patent lifetime and conduct public-private clinical trials

f) Review and update legislation on treatment

g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Strongly Agree

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

Neutral

e) Maintain capacity for 'bottom-up' innovative funding

Question 2: Please rank the suggestions in order of priority

First Priority

a) Translational research needs to be promoted

Second Priority

c) Joint academic-industry funding models

Third Priority

b) Encourage open-access sharing of data and materials

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

2015

Category of respondee

Academic researcher - Basic research

Country

Spain

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Neutral

d) Increase training for translational and clinician-scientists

Neutral

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Neutral

c) Research into the needs of carers

Neutral

d) Research into care approaches including end of life decision-making

Strongly Agree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Neutral

g) Conduct research into effects of nutrition and frailty

Neutral

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Research end of life decision making

Second Priority

h) Determine cost-effectiveness of healthcare pathways

Third Priority

e) Rethink approaches to care

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Strongly Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Ensure better patient selection/stratification

Second Priority

f) Support for high-risk projects

Third Priority

e) Rethink approach to therapeutics

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Agree

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve understanding of disease mechanisms

Second Priority

h) Develop more representative animal and cell-based models

Third Priority

b) Improve understanding of disease stages

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

d) Facilitating back-translation to models of disease

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Develop centres of excellence

Second Priority

c) Improve data and sample collection

Third Priority

a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Neutral

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Agree

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Agree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Strongly Agree

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

b) Encourage open-access sharing of data and materials

Third Priority

c) Joint academic-industry funding models

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

-understand the molecular basis of NDD -Define targets for NDD

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

2029

Category of respondee

Academic researcher - Clinical research

Country

Norway

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Neutral

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

a) Improve dialogue between researchers and wider population

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Neutral

d) Research into care approaches including end of life decision-making

Neutral

e) Rethink approaches to care

Neutral

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

f) Understand and investigate influence of comorbidities on NDD

Second Priority

h) Determine cost-effectiveness of healthcare pathways

Third Priority

Question 3: How would you define "care"?

total patients'needs are assessed, evaluated and being looked after

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

more dialogue between the different strata in health care systems (primary, local, specialized, etc) and more use of international guidelines

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

I am not sure I understand the question

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Neutral

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

c) Conduct multi-centre primary prevention studies

Second Priority

d) Ensure better patient selection/stratification

Third Priority

e) Rethink approach to therapeutics

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

information via media (television, meetings with patients' associations, press)

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Agree

d) Develop an improved understanding of the genetic basis for NDD

Agree

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Strongly Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Strongly Agree

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

f) Focus research on rare hereditary forms of disease

Second Priority

g) Establish pan-European population-based studies

Third Priority

h) Develop more representative animal and cell-based models

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

a) Interactions between cells and their surrounding intra- and extracellular environment

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Too unprecise to be answered.

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

- c) **Develop new biomarkers**
Strongly Agree
- d) **Consider regulatory approaches**
Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

- c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

- a) **Improve access to, and sharing of, infrastructure and resources**
Strongly Agree
- b) **Improve access to patient groups, samples and data**
Strongly Agree
- c) **Improve data and sample collection**
Agree
- d) **Develop a register of persons with cognitive impairment**
- e) **Develop centres of excellence**
Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Improve access to, and sharing of, infrastructure and resources

Second Priority

- b) Improve access to patient groups, samples and data

Third Priority

- c) Improve data and sample collection

Question 3: What can be done to facilitate increased sharing of data?

- Exchange of researchers and clinicians between centers

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

difficult. I am not sure I think it is a good idea any more. Best if each uses the same database collection so that exchange of information between researchers /partners can easily be done.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Often very far from clinical world, at least in Europe. So that they may tend to increase the dichotomy between basic research and clinical research, which is the opposite of what we need (translational research).

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

- a) **Need for evidence-based policy**
Agree
- b) **Ensure greater engagement with regulators**
Neutral
- c) **Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**
Neutral
- d) **Encourage industry to adopt a pre-competitive approach to research**
Neutral
- e) **Rethink patent lifetime and conduct public-private clinical trials**
Neutral
- f) **Review and update legislation on treatment**
Neutral
- g) **Review and update legislation on privacy and data disclosure**
Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) **Translational research needs to be promoted**
Strongly Agree
- b) **Encourage open-access sharing of data and materials**
Neutral
- c) **Joint academic-industry funding models**
Neutral
- d) **Simplify funding application systems**
Strongly Agree
- e) **Maintain capacity for 'bottom-up' innovative funding**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Translational research needs to be promoted

Second Priority

- d) Simplify funding application systems

Third Priority

- e) Maintain capacity for 'bottom-up' innovative funding

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

I am not sure it is the best path to follow. I think partnerships are essential, and shared projects should be more numerous, but the first thing is to teach all the potential participants to fill a standard database that can be shared in case of a common project.

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

good luck

UID

2031

Category of respondee

Academic researcher - Basic research

Country

Hungary

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Neutral

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

c) Increase overall numbers of researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Neutral

c) Research into the needs of carers

Neutral

d) Research into care approaches including end of life decision-making

Neutral

e) Rethink approaches to care

Neutral

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

f) Understand and investigate influence of comorbidities on NDD

Second Priority

g) Conduct research into effects of nutrition and frailty

Third Priority

h) Determine cost-effectiveness of healthcare pathways

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Neutral

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approach to therapeutics

Second Priority

d) Ensure better patient selection/stratification

Third Priority

f) Support for high-risk projects

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Agree

e) Determine the importance of genetic and environmental risk factors

Strongly Agree

f) Focus research on rare hereditary forms of disease

Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Strongly Agree

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve understanding of disease mechanisms

Second Priority

e) Determine the importance of genetic and environmental risk factors

Third Priority

h) Develop more representative animal and cell-based models

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

a) Interactions between cells and their surrounding intra- and extracellular environment

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

- a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Agree

b) Improve access to patient groups, samples and data

Neutral

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Develop centres of excellence

Second Priority

c) Improve data and sample collection

Third Priority

d) Develop a register of persons with cognitive impairment

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Disagree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Strongly Disagree

d) Encourage industry to adopt a pre-competitive approach to research

Strongly Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Neutral

f) Review and update legislation on treatment

Neutral

g) Review and update legislation on privacy and data disclosure

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

d) Encourage industry to adopt pre-competitive approach

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Simplify funding application systems

Second Priority

a) Translational research needs to be promoted

Third Priority

c) Joint academic-industry funding models

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

2033

Category of respondee

Academic researcher - Basic research

Country

Denmark

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Neutral

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Neutral

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Increase of clinician scientists

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Strongly Agree

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

f) Understand and investigate influence of comorbidities on NDD

Second Priority

g) Conduct research into effects of nutrition and frailty

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Disagree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

d) Ensure better patient selection/stratification

Third Priority

b) Promote development of non-pharmacological interventions

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Agree

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Neutral

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Disagree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Understand relationship between NDD and ageing

Second Priority

c) Improve understanding of disease mechanisms

Third Priority

b) Improve understanding of disease stages

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

a) Interactions between cells and their surrounding intra- and extracellular environment

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

If intervention is relative safe then I see no problem pending the patient and carers are informed

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Neutral

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

- a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Neutral

e) Develop centres of excellence

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Improve access to, and sharing of, infrastructure and resources

Second Priority

b) Improve access to patient groups, samples and data

Third Priority

e) Develop centres of excellence

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

The risk could be if the centers became subject to political fighting rather than excellence in science. Also there is a risk that the centers represent one branch of the research spectrum that thus may inhibit development of other new and promising areas

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

b) Ensure greater engagement with regulators

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

d) Encourage industry to adopt a pre-competitive approach to research

e) Rethink patent lifetime and conduct public-private clinical trials

f) Review and update legislation on treatment

g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Translational research needs to be promoted

Second Priority

e) Maintain capacity for 'bottom-up' innovative funding

Third Priority

d) Simplify funding application systems

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

2039

Category of respondee

Academic researcher - Basic research

Country

Norway

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Neutral

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

b) Improve education and training of healthcare professionals

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Improve and strengthen research in the early behavioural markers of neurodegenerative diseases (e.g., Alzheimer's). For instance a lot can be achieved by looking at language use, communication in general, and more specifically spatial language (giving/receiving directions).

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Strongly Agree

b) Survey long-term care standards and provision across Europe

Strongly Agree

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Strongly Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

f) Understand and investigate influence of comorbidities on NDD

Second Priority

h) Determine cost-effectiveness of healthcare pathways

Third Priority

b) Survey long-term care standards and provision across Europe

Question 3: How would you define "care"?

Provision of service to address the basic needs of a patient, including not only daily care (food, hygiene), but also intellectual, emotional/social related to mobility, integration etc.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Understanding co-morbidities is crucial not only for NDDs, but also in developmental disorders, and clearly we need more research in that area.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

The advantage is that patients feel more comfortable at home + it's less costly in the long run, since long-term patients will be taking costly places in hospitals which are needed for emergencies.

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

- a) **Increase involvement of individuals in research**
Agree
- b) **Promote development of non-pharmacological interventions**
Strongly Agree
- c) **Conduct multi-centre primary prevention studies**
Strongly Agree
- d) **Ensure better patient selection/stratification**
Neutral
- e) **Rethink approach to therapeutics**
Strongly Agree
- f) **Support for high-risk projects**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- c) Conduct multi-centre primary prevention studies

Second Priority

- b) Promote development of non-pharmacological interventions

Third Priority

- e) Rethink approach to therapeutics

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

- By raising better awareness of the value and spin-off effects of research.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

- a) **Understand relationship between neurodegenerative disease and ageing**
Strongly Agree
- b) **Improve understanding of disease stages**
Strongly Agree
- c) **Improve understanding of disease mechanisms**
Strongly Agree
- d) **Develop an improved understanding of the genetic basis for NDD**
Strongly Agree
- e) **Determine the importance of genetic and environmental risk factors**
Strongly Agree
- f) **Focus research on rare hereditary forms of disease**
Neutral
- g) **Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**
Strongly Agree
- h) **Develop more representative animal and cell-based models of disease**
Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

- e) Determine the importance of genetic and environmental risk factors

Second Priority

- a) Understand relationship between NDD and ageing

Third Priority

- d) Develop an improved understanding of the genetic basis

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

- d) The biological basis of behavioural and psychological symptoms

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Strongly Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Develop a register of persons with cognitive impairment

Second Priority

c) Improve data and sample collection

Third Priority

a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?

Better legislation across EU borders

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Centres of excellence have one major negative effect: they take away much needed resources from other (smaller, and not necessarily worse) teams, who might struggle to produce results of comparable impact.

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Agree

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Agree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Need for evidence-based policy

Second Priority

e) Rethink patent lifetime and conduct public-private clinical trials

Third Priority

e) Rethink patent lifetime and conduct public-private clinical trials

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) **Translational research needs to be promoted**
Strongly Agree
- b) **Encourage open-access sharing of data and materials**
Agree
- c) **Joint academic-industry funding models**
Agree
- d) **Simplify funding application systems**
Strongly Agree
- e) **Maintain capacity for 'bottom-up' innovative funding**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

- a) Translational research needs to be promoted

Third Priority

- d) Simplify funding application systems

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Research in early NDD behavioral pathology, language, orientation, memory, but other symptoms as well. Longitudinal studies needed here.

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Interdisciplinary research should also involve psychologists, cognitive scientists (e.g., there are good memory models for healthy typical populations) neuro/psycho-linguists.

Question 3: Is there anything else you would like to tell us?

UID

2061

Category of respondee

Academic researcher - Basic research

Country

United Kingdom

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

c) Increase overall numbers of researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

n/a

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Neutral

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Neutral

e) Rethink approaches to care

f) Understand and investigate influence of comorbidities

g) Conduct research into effects of nutrition and frailty

h) Determine cost-effectiveness of healthcare pathways

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

b) Promote development of non-pharmacological interventions

c) Conduct multi-centre primary prevention studies

d) Ensure better patient selection/stratification

e) Rethink approach to therapeutics

f) Support for high-risk projects

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

- a) Understand relationship between neurodegenerative disease and ageing**
Strongly Agree
- b) Improve understanding of disease stages**
Strongly Agree
- c) Improve understanding of disease mechanisms**
Strongly Agree
- d) Develop an improved understanding of the genetic basis for NDD**
Strongly Agree
- e) Determine the importance of genetic and environmental risk factors**
Strongly Agree
- f) Focus research on rare hereditary forms of disease**
Strongly Agree
- g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**
Strongly Agree
- h) Develop more representative animal and cell-based models of disease**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- c) Improve understanding of disease mechanisms

Second Priority

- d) Develop an improved understanding of the genetic basis

Third Priority

- h) Develop more representative animal and cell-based models

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

- c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

I feel that it is critical to always validate results from cell-models in some sort of animal system. Perhaps initially in invertebrate models, but ultimately at least a rodent model should be tested for positive effects.

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

- a) Redefine and standardise disease definitions and diagnosis**
Agree
- b) Redefine and harmonise clinical endpoints and outcomes**
Neutral
- c) Develop new biomarkers**
Strongly Agree
- d) Consider regulatory approaches**
Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

- a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

- a) Improve access to, and sharing of, infrastructure and resources**
Agree
- b) Improve access to patient groups, samples and data**
Agree
- c) Improve data and sample collection**
Neutral
- d) Develop a register of persons with cognitive impairment**

Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Develop centres of excellence

Second Priority

a) Improve access to, and sharing of, infrastructure and resources

Third Priority

b) Improve access to patient groups, samples and data

Question 3: What can be done to facilitate increased sharing of data?

I would suggest a two-pronged approach. First, provide an incentive to contribute data; perhaps this could be a small amount of funding for the project or better access to studentships. Secondly, providing security for the data, and establish provisions as to how this data can be used.

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

One problem is, if the data is open access, how do we control the quality of the analyses that others perform with this data. Perhaps an approval process needs to be in place to ascertain who is truly qualified to handle such data.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

No; I believe it is an excellent idea.

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

b) Ensure greater engagement with regulators

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

d) Encourage industry to adopt a pre-competitive approach to research

e) Rethink patent lifetime and conduct public-private clinical trials

f) Review and update legislation on treatment

g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Strongly Agree

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Translational research needs to be promoted

Second Priority

e) Maintain capacity for 'bottom-up' innovative funding

Third Priority

d) Simplify funding application systems

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

n/a

Question 2: Do you have any comments on how to implement the above suggestion(s)?

n/a

Question 3: Is there anything else you would like to tell us?

n/a

UID

2065

Category of respondee

Academic researcher - Clinical research

Country

Ireland

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

d) Increase training for translational and clinician-scientists

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Agree

b) Survey long-term care standards and provision across Europe

Strongly Agree

c) Research into the needs of carers

Strongly Agree

d) Research into care approaches including end of life decision-making

Strongly Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approaches to care

Second Priority

h) Determine cost-effectiveness of healthcare pathways

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

f) Support for high-risk projects

Second Priority

a) Increase involvement of individuals in research

Third Priority

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Strongly Agree

e) Determine the importance of genetic and environmental risk factors

Strongly Agree

f) Focus research on rare hereditary forms of disease

Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Strongly Agree

h) Develop more representative animal and cell-based models of disease

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

g) Establish pan-European population-based studies

Second Priority

e) Determine the importance of genetic and environmental risk factors

Third Priority

c) Improve understanding of disease mechanisms

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

a) Interactions between cells and their surrounding intra- and extracellular environment

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Strongly Agree

b) Redefine and harmonise clinical endpoints and outcomes

Strongly Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Neutral

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve data and sample collection

Second Priority

a) Improve access to, and sharing of, infrastructure and resources

Third Priority

e) Develop centres of excellence

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

b) Ensure greater engagement with regulators

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

d) Encourage industry to adopt a pre-competitive approach to research

e) Rethink patent lifetime and conduct public-private clinical trials

f) Review and update legislation on treatment

g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Strongly Agree

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Translational research needs to be promoted

Second Priority

d) Simplify funding application systems

Third Priority

e) Maintain capacity for 'bottom-up' innovative funding

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

2104

Category of respondee

Academic researcher - Basic research

Country

Portugal

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

b) Improve education and training of healthcare professionals

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Strongly Agree

c) Research into the needs of carers

Strongly Agree

d) Research into care approaches including end of life decision-making

Strongly Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Strongly Agree

g) Conduct research into effects of nutrition and frailty

Strongly Agree

h) Determine cost-effectiveness of healthcare pathways

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approaches to care

Second Priority

b) Survey long-term care standards and provision across Europe

Third Priority

c) Research into the needs of carers

Question 3: How would you define "care"?

Care is the provision of medical, psychological and physical comfort to patients.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

No.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

According to family needs.

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Strongly Agree

c) Conduct multi-centre primary prevention studies

Strongly Agree

d) Ensure better patient selection/stratification

Strongly Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

b) Promote development of non-pharmacological interventions

Third Priority

c) Conduct multi-centre primary prevention studies

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Awareness about research going on NDD and importance of biological contribution from patients.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

In Portugal prevention is far from good, because even simple measurements, like blood pressure and some important and easily assessed biochemical parameters, are not sufficiently routine measured and taking in account to prevent cognitive pathologies.

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Strongly Agree

e) Determine the importance of genetic and environmental risk factors

f) Focus research on rare hereditary forms of disease

Strongly Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Neutral

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve understanding of disease mechanisms

Second Priority

f) Focus research on rare hereditary forms of disease

Third Priority

h) Develop more representative animal and cell-based models

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

No.

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Strongly Agree

b) Redefine and harmonise clinical endpoints and outcomes

Strongly Agree

c) **Develop new biomarkers**

Strongly Agree

d) **Consider regulatory approaches**

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) **Improve access to, and sharing of, infrastructure and resources**

Neutral

b) **Improve access to patient groups, samples and data**

Agree

c) **Improve data and sample collection**

Agree

d) **Develop a register of persons with cognitive impairment**

Agree

e) **Develop centres of excellence**

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) **Need for evidence-based policy**

Strongly Agree

b) **Ensure greater engagement with regulators**

Strongly Agree

c) **Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**

Strongly Agree

d) **Encourage industry to adopt a pre-competitive approach to research**

Strongly Disagree

e) **Rethink patent lifetime and conduct public-private clinical trials**

Strongly Agree

f) **Review and update legislation on treatment**

Strongly Agree

g) **Review and update legislation on privacy and data disclosure**

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Need for evidence-based policy

Second Priority

e) Rethink patent lifetime and conduct public-private clinical trials

Third Priority

g) Review and update legislation on privacy and data disclosure

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

no

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) **Translational research needs to be promoted**

Strongly Agree

b) Encourage open-access sharing of data and materials

Neutral

c) Joint academic-industry funding models

Neutral

d) Simplify funding application systems

Neutral

e) Maintain capacity for 'bottom-up' innovative funding

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

2153

Category of respondee

Academic researcher - Socio-economic or healthcare research

Country

United Kingdom

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

More emphasis on career development in psychosocial research

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Disagree

b) Survey long-term care standards and provision across Europe

Agree

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approaches to care

Second Priority

b) Survey long-term care standards and provision across Europe

Third Priority

c) Research into the needs of carers

Question 3: How would you define "care"?

I'm not convinced that we lack a definition of 'care' - it is the generic term used to describe the support and assistance provided to the person (in this case with dementia). It may apply to a care system, or at its most crucial level to an interaction with the person with dementia. It is a dynamic process. What is more difficult is to define the quality of care, to describe and replicate good quality care and to train staff and support families in delivering it.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

We need to develop better measures of outcome (including quality of life and well being) especially for those with advanced dementia. Then research could inform the development of care systems. Essentially, care systems need to be person centred, evidence-based, and involve the person with dementia and their families fully in all aspects.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Perversely by improving the quality of care in alternatives to home, so that those remaining at home have a real choice. Assistive technology is not the answer, although it can help - need skilled practitioners to devise packages of care with the person and family, and trained support workers / befrienders to deliver it.

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Strongly Agree

c) Conduct multi-centre primary prevention studies

Strongly Agree

d) Ensure better patient selection/stratification

Strongly Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Disagree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Promote development of non-pharmacological interventions

Second Priority

a) Increase involvement of individuals in research

Third Priority

c) Conduct multi-centre primary prevention studies

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Ensure the research gives something back to the participant - involvement, being part of something special, personal contact, clinicians who support research whole-heartedly, not just for their own benefit.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Physical and mental exercise

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Agree

d) Develop an improved understanding of the genetic basis for NDD

Agree

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Disagree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Understand relationship between NDD and ageing

Second Priority

b) Improve understanding of disease stages

Third Priority

g) Establish pan-European population-based studies

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

b) Neuronal inflammation

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Neutral

b) Redefine and harmonise clinical endpoints and outcomes

Strongly Agree

c) Develop new biomarkers

Neutral

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

b) Linking to treatment responses

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Neutral

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Strongly Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Develop a register of persons with cognitive impairment

Second Priority

e) Develop centres of excellence

Third Priority

a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?

Make it a requirement of grant-funding

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

May be difficult to secure informed consent from participants for all future uses. Disincentive for those undertaking the difficult task of collecting the data.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

May become too large to be creative and effective

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Strongly Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Strongly Agree

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Neutral

f) Review and update legislation on treatment

Disagree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Need for evidence-based policy

Second Priority

- c) Facilitate research in areas outside university and hospital sectors

Third Priority

- b) Ensure greater engagement with regulators

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Allowing recruitment of participants on an 'opt-out' basis

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Neutral

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- d) Simplify funding application systems

Second Priority

- e) Maintain capacity for 'bottom-up' innovative funding

Third Priority

- b) Encourage open-access sharing of data and materials

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Many longitudinal studies offer this facility, subject to certain controls e.g. the CFAS study in the UK

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Greater involvement of people with dementia and care-givers in the research funding process (as with the Alzheimer's Society in the UK)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

2162

Category of respondee

Academic researcher - Basic research

Country

United Kingdom

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Encourage more multi-disciplinary research.

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

b) Survey long-term care standards and provision across Europe

c) Research into the needs of carers

d) Research into care approaches including end of life decision-making

e) Rethink approaches to care

f) Understand and investigate influence of comorbidities

g) Conduct research into effects of nutrition and frailty

h) Determine cost-effectiveness of healthcare pathways

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Strongly Agree

c) Conduct multi-centre primary prevention studies

Strongly Agree

d) Ensure better patient selection/stratification

Strongly Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Increase involvement of individuals in research

Second Priority

- f) Support for high-risk projects

Third Priority

- c) Conduct multi-centre primary prevention studies

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Develop a register of potential volunteers prior to the development of NDD. Provide information at this stage so potential research participation has been considered prior to any diagnosis.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Not sure we are in such a position at present.

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Strongly Agree

e) Determine the importance of genetic and environmental risk factors

Strongly Agree

f) Focus research on rare hereditary forms of disease

Neutral

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- b) Improve understanding of disease stages

Second Priority

- h) Develop more representative animal and cell-based models

Third Priority

- c) Improve understanding of disease mechanisms

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

- b) Neuronal inflammation

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

No, it is important to look in the whole organism. Interactions between systems is a critical factor that is overlooked.

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

- a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Strongly Agree

e) Develop centres of excellence

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Improve access to, and sharing of, infrastructure and resources

Second Priority

d) Develop a register of persons with cognitive impairment

Third Priority

b) Improve access to patient groups, samples and data

Question 3: What can be done to facilitate increased sharing of data?

There is a need to ensure equal recognition for all parties involved.

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

This will involve something of a paradigm shift as the trend is for academic groups to be increasingly protective of their own data. Currently used assessment mechanisms of research output/quality necessitate a parochial and competitive mode of operating (within institutions to some extent and certainly between institutions) which is at odds with true data sharing.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

There may be more value in developing 'centres' which are flexible collaborations across research teams. A fixed (geographical) centre of excellence model risks small but excellent research teams located elsewhere being neglected in funding terms. The approach of the Wellcome Trust for example, of pumping vast amounts of funding into centres in a very small group of academic locations leaves great teams elsewhere missing out on funding which could lead to major advances.

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Strongly Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Neutral

d) Encourage industry to adopt a pre-competitive approach to research

Strongly Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Agree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Encourage industry to adopt pre-competitive approach

Second Priority

e) Rethink patent lifetime and conduct public-private clinical trials

Third Priority

f) Review and update legislation on treatment

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Translational research needs to be promoted

Second Priority

d) Simplify funding application systems

Third Priority

c) Joint academic-industry funding models

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?